MASTER OF SCIENCE BY RESEARCH

A qualitative systematic review of the use of self-management as a coping strategy for patients with chronic obstructive pulmonary disease at the end of life

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Award date:
2018

Awarding institution:
Coventry University

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By

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Master of Science by Research

May 2018

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A thesis submitted in partial fulfilment of the University's requirements for the Degree of Master of Science by Research

May 2018

Certificate of Ethical Approval

Applicant: Louise Bolton

Project Title:

A qualitative systematic review of using self-management as a coping strategy to meet the needs of patients with advanced chronic obstructive pulmonary disease at the end of life.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval: 10 January 2018

Project Reference Number: P62130

Acknowledgements

I would like to thank my academic supervisory team, Dr Elizabeth Horton, Dr Louise Sewell and Professor Jane Coad for their continued support and constructive guidance to assist in my development as a researcher and improve my work. Each of you has made this journey such an enjoyable and life-changing experience and have made my experience at Coventry University a true pleasure.

I would also like to thank my clinical supervisor, Dr Charlotte Bolton for her support, encouragement and time that has exceeded any expectation and has been given through utter kindness.

Finally, to my husband Mike, son James and my Dad. Thank you for your encouragement in me to pursue my dreams, your endless patience and understanding.

I would like to dedicate this dissertation in loving memory of my Mum.

Abstract

Introduction: Patients with COPD experience symptoms of breathlessness, fatigue, reduced mobility and disease related anxiety and depression which impacts upon their quality of life. Throughout disease progression into the palliative phase of COPD, these symptoms increase resulting in social isolation and increased dependence upon others. A holistic and consistent approach to palliative care within COPD remains absent with many patients' continuing to have limited access to palliative care resources. Self- management enhancing interventions have been used successfully within earlier stages of disease progression and have the potential to impact upon the enhanced symptoms present for patients with COPD at the end of life. Therefore, the aim of this dissertation is to determine if the use of self- management interventions are a potential coping strategy for patients with COPD at the end of life.

Methods: A qualitative systematic review has been undertaken to gain the perspectives of patients, carers and healthcare professionals upon the use of self-management interventions for people with COPD at the end of life. 25 studies were identified for inclusion following the application of pre-defined inclusion and exclusion criteria. The review findings were analysed using a meta-ethnographical approach to create new concepts upon the use of self-management as a coping strategy for patients with COPD at the end of life.

Findings: The use of self-management as a coping strategy for patients with COPD at the end of life was found to be acceptable to patients and healthcare professionals, and was perceived as having a positive effect upon self-confidence and perceived ability to cope.

Considerations are required prior to implementation of interventions aimed at this cohort of patients including the potential non-acceptance of having COPD by patients. In turn, this affects the perceptions of healthcare professionals upon the patients desire to change behaviours. Healthcare professionals find patients with COPD at the end of life complex to manage and require further education and training upon how to facilitate behaviour change within the palliative phase of disease progression.

Patients with COPD at the end of life form dependence upon others therefore the use of self-management interventions alone would not be appropriate or realistic.

Conclusion: The use of self-management for patients with COPD at the end of life has the potential to impact upon their abilities to cope with the symptoms of advanced disease progression and improve their quality of life. Further work is required to consider a supported model of self-management for patients with COPD at the end of life to meet their physical, psychological and social needs.

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Chapter 1.0 – Introduction

This dissertation aims to explore the use of self-management interventions as a coping strategy for patients with advanced chronic obstructive pulmonary disease (**COPD**) at the end of life explored through a systematic review of the perceptions of patients, carers and healthcare professionals.

This chapter identifies the issues to be explored within this dissertation giving context and an evidence-based rationale. This chapter consists of five sections. The first section (1.1) explains the impact of COPD upon both the individual and the economy and identifies the gaps within palliative care provision. Models of self-management may allow for improved coping ability for these patients. This rationale underpins the aims and objectives detailed within section 1.2. The third section (1.3) outlines the thesis structure and rationale for chapters 2 to 7. Section 1.4 gives the background of the researcher.

1.1 – Context and rationale

Chronic Obstructive Pulmonary Disease (COPD) is characterised by the presentation of irreversible airflow limitation leading to symptoms of dyspnoea, increased sputum production, persistent cough and wheezing and often results in systemic co-morbidities that include cardiac disease, diabetes mellitus, hypertension, osteoporosis and psychological disorders (World Health Organisation 2010), making COPD a serious life-limiting condition. Within the United Kingdom, over 1.2 million individuals are currently diagnosed with COPD and over 30,000 deaths are attributed to the condition per year. (World Health Organisation 2010). COPD is a major cause of morbidity and mortality and is reported as being the third biggest cause of death worldwide (World Health Organisation 2016). It is evidenced that 1.7% of all hospital admissions are related to COPD within the United Kingdom (British Lung Foundation 2016), utilising a notable quantity of the £1.9 billion of the economic impact per annum (British Lung Foundation 2017).

The impact of this life limiting condition goes beyond physical symptoms of breathlessness, decreased mobility, fatigue and weight loss progressing to impairment upon individuals' employment and daily living resulting in social isolation, co-morbid depression and anxiety (Elkington et al. 2004). The symptom burden of COPD is estimated to be greater than that of a person with terminal lung cancer (Gore et al. 2000). For individuals living with COPD, this disease progression often leads towards palliative symptom management encompassing the patients' ability to cope and manage their illness effectively in the face of impending death (Public Health England 2013). A holistic, appropriate and consistent approach to palliative care within COPD remains absent (Elkington et al 2005) with many patients' continuing to have limited access to palliative care resources (Habraken et al. 2007).

Effective self-management facilitates patients to make decisions and participate in behaviours impacting upon their health and is an expected COPD management strategy within the United Kingdom, with guidance given that a self-management plan or educational

package should be bespoke to the individual needs of the patient at their specific time of disease progression (National Institute for Health and Care Excellence 2010). Self-management interventions have demonstrated a positive impact upon people's ability to manage their symptoms at earlier stages in disease progression where participants are able to attend educational sessions (Apps et al. 2013). However, this could prove to be less successful for patients at the end of life who face decreased mobility, fatigue and social isolation.

Variations within definitions of self-management interventions and their impact lead to challenges in interpretation of their effectiveness. It is well documented that self- management has a strong focus upon the participant taking responsibility for their own health and social outcomes but how that effective that change in self-management is gained is variable. This is an interesting concept for patients with COPD at the end of life who may struggle to self-manage due to significant anxiety when facing overwhelming breathlessness and fear of death. For self-management to be successful and sustainable, the individual must alter the method behind their thinking alongside how they behave and emotionally react to their chronic condition, this in turn gives them the ability to respond to the demands of the disease (Barlow et al. 2002) and is believed to be fundamental in sustaining better control of one's health (Effing et al. 2012).

Differences within self-management intervention delivery are vast with some adopting a brief approach such as a leaflet (Leiva-Fernández et al. 2014) or the use of technology based education programmes (McCabe, McCann and Brady 2017), with others offering a more comprehensive self-management manual with healthcare professional contact based upon motivational interviewing concepts (Apps et al. 2013). Outcome measures for these studies are variable, utilising a number of validated numerical assessment tools to evaluate the impact of self-management upon specific symptoms alongside obtaining the views and opinions of patients, their carers and healthcare professionals to determine interventions success making it difficult to draw definite conclusions by comparison.

Evaluating self-management and coping interventions for people with COPD at the end of life has not been explicitly explored, yet studies have included this cohort of patients when testing such interventions. Symptoms of COPD at the end of life are commonly predicted and often result in increasing dependence upon family, carers and healthcare services to deliver support and treatment. Despite the knowledge of these symptoms, inequitability of palliative care provision for those living with COPD when compared to other illnesses is present and requires action to ensure patient choice is supported within their last year of life and their death (Gore, Brophy and Greenstone 2000).

Should self-management be a coping strategy for these patients by acquisition of coping skills and increased self-efficacy, the need for access to healthcare services at this stage within disease progression could decrease benefiting both the individual and healthcare providers.

1.2 – Aims and Objectives

The aim of this dissertation is to evaluate the perceived impact of self-management as a coping strategy for patients with COPD at the end of life by exploring the views of patients, their carers and healthcare professionals.

A qualitative systematic review was undertaken of all available qualitative literature to achieve the following objectives:

- To identify relevant empirical qualitative research that has examined the perspectives of patients, carers and healthcare professionals upon the use of self-management interventions for people with COPD at the end of life.
- To determine, from drawing upon the literature, at what point within COPD disease progression a self-management programme would benefit a patient with COPD at the end of life.
- To critically appraise and synthesise this data to identify, explore and explain if enhancing self-management is a potential coping strategy for patients with COPD at the end of life.

1.3 – Structure of the Dissertation

Chapter 2 gives a review of the current literature upon palliative care provision for patients with COPD and explores the use of self-management interventions used with this group of patients. Definitions of end of life COPD and self-management for use within this dissertation are given within this chapter. The study methodology and underpinning philosophy is explained within chapter 3. Chapter 4 gives an explanation of the systematic review methods used within this dissertation. The findings of this systematic review are explained within chapter 5, identifying new themes from the perceptions of patients and healthcare professionals upon the use of self-management at the end of life. Chapter 6 discusses the key findings from this dissertation giving recommendations for clinical practice and future research.

1.4 – Background of the Researcher

Throughout this dissertation an objective voice is adopted, however, to set the scene in the researcher, a reflective personal voice is used. I have been a registered adult nurse since 2005 and have specialised in Respiratory Medicine for 11 years undertaking senior nursing positions within that time. I have extensive experience of caring for patients with COPD amongst other chronic respiratory conditions, giving me insight into the gaps within care and treatment for these patients. Additionally, I hold experience of working within clinical education, allowing me to understand education theory and implement this within clinical practice.

My areas of particular interest within COPD are advanced disease progression and end of life care with the passion to address the inadequacies in support at the end of life present for this cohort of patients. This experience has allowed me to observe how challenging, demanding and at times traumatic the last year of life is for someone living with COPD and their families. The patients do not wish to spend this time recurrently admitted into hospital, often for non-medical reasons, yet the support and facilities are not available for them to remain at home should that be their choice. I have witnessed the increased anxiety and disruption COPD causes at the end of life, not only to the patient but to their family and carers and I am dedicated to improving this experience for patients to allow them to live their last year of life with dignity and comfort.

This dissertation is part of my first undertaking of clinical research, allowing me to address a research question devised from my observations within clinical practice to contribute to the existing knowledge base within this field and to identify areas of further research within which I will continue my clinical academic career whilst striving to contribute to improve patient care.

Chapter 2.0 – Literature Review

This chapter explores the major concepts to be investigated within this dissertation, providing an evidence-based rationale for this study. This chapter is divided into six sections to allow for a structured exploration of the relevant literature. The first section (2.1) provides discussion around the theory underpinning self-management as a concept and the intervention to be evaluated within this dissertation. Following this, section 2.2 synthesises the literature when defining self-management and gives the definition to be used within this study prior to exploration of the use of self-management specifically within COPD (2.3). The evidence relating to patients' self-management needs at the end of life will then be explored throughout section 2.4 through identification of key symptomatic needs. Section 2.5 explores the issues relating to defining end of life for people with COPD to be used throughout this systematic review and assists with the formation of study inclusion and exclusion criteria. Section 2.6 provides a summary of the literature review further explaining the rationale for this research. The underpinning research philosophy and methodology is explained within Chapter 3. The systematic review method is described within Chapter 4.

2.1 Theory of Self-Management

Self-management, as a model of behaviour change is underpinned by the cognitive theory of self-efficacy, first explored by Bandura (1977). Within cognitive theory, cognition assists within thought processes of changing behaviour, however actual change in behaviour occurs once the person gains a feeling of self-efficacy or mastery when accomplishing a new performance (Bandura 1977). One influence upon self-efficacy is that of an individual's perceived self-efficacy towards a new task or behaviour. Perceived self-efficacy is concerned with an individual's self-belief around their capability of performance mastery of a specific task and is particularly significant within self-management as it influences how individuals feel, think and are motivated (Bandura 1977).

For older people with declining health status, a decline in self-efficacy for specific tasks is common as the impact of biological changes upon health and functioning may remove feelings of mastery over time (Bandura 1994). Therefore, within COPD disease progression, new demands on coping are made requiring individuals to further develop perceived self-efficacy and self-efficacy to improve their health and social well-being at each stage of deterioration.

When beginning to explore the practicalities of self-management, it must be acknowledged that interventions leading to behaviour change are complex and evaluation is difficult due to differences of delivery and setting leading to challenges when trying to identify effective components within interventions. An attempt to overcome these challenges are practically discussed within the Behaviour Change Technique Taxonomy (Michie et al. 2013). Having undertaken a robust content analysis of demonstrated reliability across 221 behavioural change intervention descriptors within papers and manuals, Michie et al. (2013) developed the taxonomy aiming to promote precise reproduction of behaviour change interventions. The taxonomy gives a hierarchy of techniques (appendix A) known to be effective and hopes to assist with the formation of behaviour change interventions. This taxonomy is of use when

related behaviour change. To begin to define self-management as a behaviour change concept, an understanding of the underpinning theory is paramount.

2.2 - Definition of Self-Management

Defining self-management, specifically related to improving patient care and experience within chronic condition management has been attempted many times, both explicitly as a definition and through components included within the testing of self-management interventions. It is acknowledged that self-management is a process of importance to assist with core improvement for long-term conditions (Wagner 1998). One early definition which remains frequently referred to is the work of Barlow et al. (2002) who stated self- management encompasses an individual's skill of symptom control, treatment and the physical and psychological effects and changes in daily living essential to live with a chronic condition. Lifestyle changes are largely present throughout COPD disease progression and include adaptation to decreased mobility, increased breathlessness and related anxiety as each individual adapts and self-manages naturally over time. A facilitated self-management approach aims to enhance those skills to facilitate more effective individual self- management.

An understanding of the process of behaviour change is required when defining self-management (Barlow et al. 2002), however, understanding the required elements to be delivered for success is of equal relevance. Self-management research specifically within COPD uses a variety of definitions with most stating the necessity for an element of formal education, most noticeably within the work of Bourbeau et al. (2003) whose self- management intervention considered of a large proportion of health education. Other elements found to be crucial when defining self-management are the inclusion of problem solving elements, in turn leading to the acquisition of decision making skills (Lorig and Holman 2003), with the ultimate goal being sustained change in health and social behaviour (Effing et al. 2012).

A valuable attempt to finalise a definition of self-management within COPD was a result of an international expert group consensus (Effing et al. 2016) where 28 experts from the field of

self-management within COPD gave opinions and perceptions to create a conceptual definition. They concluded that a self-management intervention has structure, yet is adapted to the individual with the main outcomes of motivation, engagement and support to complete and maintain behaviour change with the new skill acquisition. The significance of this work must be acknowledged; given the contributors are international COPD self-management research leaders. For this systematic review, consideration must be given to the differences between self-management within a chronic condition and self-management within the palliative phase of a chronic condition Johnston et al. (2014). Throughout the palliative phase, healthcare professionals should assist with 'supported self-management' as opposed to attempting facilitation of patients becoming independent at managing their condition at the end of life (Johnston et al. 2014). On entering the palliative phase of disease progression, self-management may hold different outcome expectations, including maintenance rather than reduction of symptoms, maintain one's own identity, yet still achieving mastery of coping skills to prevent the need to seek assistance (Corner 2002), fitting with the theory of self- efficacy (Bandura 1977) discussed within section 2.1.

The definition of self-management to be used within this systematic review has been formulated with consideration given to the theoretical underpinning of self-management (Bandura 1994), alongside the extraction of successful educational components from existing self-management intervention studies within COPD, such as action planning and goal setting (Apps et al. 2013). Exacerbation management techniques (Gadoury et al. 2005) and the interpretation and application of a COPD specific self-management model (Wagg 2012) were evaluated alongside the hierarchical list of behavioural change techniques found within the work of Michie et al (2013).

This systematic review will include papers meeting one or more of the following self-management elements:

- **Decision-making techniques**
- **Symptom monitoring skills**
- **Action planning and Goal setting**
- **Emotional management techniques**
- **Problem solving techniques**
- **Increased participant confidence**
- **Behavioural-change techniques**
- **Exacerbation management techniques**
- **New knowledge component**
- **Practicing new behaviours**

2.3 - Self-management in COPD

The use of self-management within long-term conditions is widely encouraged throughout healthcare within the United Kingdom (NHS England 2017). A predicted burden upon healthcare services across the world is inevitable due to increase life expectancies, bringing a greater number of people with chronic illness (World Health Organisation 2010). The nature of living with a chronic disease requires an understanding by the patient of the absence of cure, resulting in lifelong management and the need for adaptation to managing changing elements of their health status (Lorig and Holman 2003). COPD is no exception to this, with a trajectory of increasing symptoms and instability requiring the patient to respond to new problems and needs.

The use of self-management interventions within cohorts of patients with COPD has a substantial evidence base. Evaluating the effect of these interventions as a whole brings difficulties due to differences between the styles of intervention delivery, the content within each intervention, the varied use of differing outcome measures and the baseline characteristics of participants covering all stages of disease progression whom display very different needs.

Early work upon the use of self-management within COPD was undertaken by Bourbeau et al.(2003). This multicentre randomised trial compared the impact of a self-management intervention upon disease symptoms such as breathlessness and sputum production, exercise tolerance, overall health status and hospital utilisation. The intervention group received individualised education and exercise sessions each week for a total of eight weeks over a twelve-month period, alongside a self-help book and disease management action plan. The intervention group also received telephone follow up and counselling each week for eight weeks and monthly for the duration of the study. A control group for comparison received usual care. Results demonstrated a reduction in hospital admissions of 38.9% within the intervention group, suggesting the intervention had impact upon the participants

ability to self-manage, however from the presentation of results it is unclear as to which component of the intervention had most effect, the education and exercise sessions or the case manager follow up support. The baseline characteristics of the study participants suggest they had severe or very severe COPD (mean FEV^1 % predicted of 46%) therefore it could be assumed that these patients were therefore approaching the end of life. This intervention did provide a significant amount of support to enhance self-management when compared to other interventions for this cohort of patients.

Health related quality of life was measured using the St George's Respiratory Questionnaire – SGRQ (Jones et al. 2009). The SGRQ is designed to measure health status impairment and health related quality of life within respiratory disease, with lower scores indicating better health status (Jones et al. 2009). The tool is a validated self-assessment tool developed using a rigorous methodology (Meguro et al. 2007) and is widely adopted when testing intervention impact upon respiratory symptoms (Jones et al. 2009). The questionnaire is constructed of 76 weighted items to give scores within three domains, symptoms, activity and impact (Monninkhof et al. 2003). The lower the given overall score, the less impact symptoms are having upon health related quality of life. When using the tool to evaluate intervention impact, it is evidenced that a change of four more of a score indicates clinical significance (Jones and Bosh 1997). Within Borbeau's (2003) study, improvements of symptoms sustained at 12-months post intervention are demonstrated including the symptomatic reduction of breathlessness and improved total patient health status, both symptoms deemed as very important to those living with COPD at the end of life, as dying with breathlessness has been identified as an unsurprising fear for this cohort of patients (Gardiner et al. 2009a).

A study of similar intervention design and outcome measures was that of Monninkhof et al. (2003) whom undertook a randomised controlled trial testing the impact of the COPE self-management intervention. 127 participants were enrolled into the intervention group with a demographically similar 121 participants within a control group receiving usual care. The

baseline demographics suggest some of enrolled participants had moderate to severe COPD (mean FEV^1 % predicted – 56.1 ± 15.4) and ten participants died throughout the study, suggesting the results may be relevant to those with COPD at the end of life. The intervention group received a formal education course of five two-hour group sessions alongside an exercise programme of two sessions per week. Participants also received a booklet containing a self-treatment action plan and disease specific information. The study results, produced at two years post intervention delivery demonstrated no clinically significant improvement in healthcare related quality of life, challenging the results presented by Borbeau (2003). No difference within respiratory symptoms and overall well-being were observed and similarly participant self-confidence was not improved. The study population's baseline characteristics demonstrated the baseline health related quality of life was remarkably high, with the research team suggesting this would impact the potential for improvement. The demographics also demonstrate the increased severity of the study populations' disease progression, asking the question of the appropriateness of self- management for those already receiving maximum therapeutic treatment. Interestingly neither this study nor the work of Borbeau (2003) attempted to understand the patients' perspectives of self-management which may have enhanced the study's findings to enable an insight into how the interventions made participants feel and highlight new and meaningful ideas for inclusion with interventions.

This study should not be interpreted in isolation as other work has demonstrated differing results with similar participant populations such as the work of Effing et al. (2011). This randomised controlled trial, the COPE-active study delivered a physiotherapist-led training programme to 77 participants within an intervention group in addition to an existing self-management programme to review its impact upon exercise capacity, health-related quality of life, anxiety and depression. The training programme was delivered two to three times per week for six months with optional continuation for a further five months.

Once weekly sessions were delivered at participants' homes aiming to facilitate behaviour change (Effing et al. 2011). Improvements within the symptomatic impact of breathlessness were observed within the intervention group, reinforcing the evidenced link between patient desensitisation to breathlessness and increased exercise tolerance (Strijbos et al. 1996), suggesting that for a self-management intervention to improve the symptomatic burden of breathlessness, an exercise component is required. This may however pose challenge to interventions focussing upon those with COPD at the end of life due to the impact of disease progression causing increased breathlessness and decreased mobility (Elkington et al. 2004).

No improvements of significance were demonstrated upon participant's health related quality of life, anxiety or depression demonstrating that these symptoms require much more than an exercise component of an intervention to lead to improvement of symptoms. This point was explored within the innovative work of Apps et al. (2013) whom developed the self-management programme of activity, coping and education (SPACE) for COPD within a pilot study utilising co-creation of the intervention with patients living with COPD. The study gained perceptions of patients to assist in the development of a self-management support manual to be utilised alongside the voiced patient preference of healthcare professional contact to formulate the intervention, the first study of its kind to utilise the valuable resource of those living with the condition to impact upon its creation. Upon development of the intervention, the pilot study consisted of 37 participants from primary care settings undergoing an initial face to face self-management consultation with telephone follow up prior to utilisation of the SPACE for COPD manual to assist coping over a six-week period, alongside an individualised COPD action plan.

SPACE for COPD manual chapter titles

- Disease information
- Increasing fitness
- Goal setting
- Managing stress and emotion
- Breathing techniques
- Energy conservation
- Medication management

Results from the pilot study (Apps et al. 2013) demonstrated an improvement in symptomatic breathlessness burden and improved exercise tolerance, measured using the Self-Report Chronic Respiratory Questionnaire (CRQ-SR). The CRQ-SR is a replicable and reliable tool to assess health status among patients with COPD (Williams et al. 2001). The pilot study demonstrated no improvement upon participants' level of depression however it is necessary to acknowledge the baseline depression scores being remarkably low, reducing the potential for impact upon this disease symptom. Anxiety levels were measured and although did not improve enough to display statistical significance, sufficient decrease in scores were observed to give value to the interventions impact upon anxiety.

The SPACE for COPD intervention was then further tested within a single-blinded randomised controlled trial of 184 participants' undertaking the intervention programme (Mitchell et al. 2014). The intervention delivery remained as within the pilot study. Outcome measures were taken at six weeks and six months' post intervention, primarily using the dyspnoea domain of the CRQ-SR. Secondary outcomes, utilising other domains of the CRQ- SR included participants level of anxiety, depression, self-efficacy, disease knowledge, healthcare utilisation and exercise performance. The intervention resulted in improvements in CRQ-SR dyspnoea scores at six weeks however this significance was not sustained at six months. Initial improvements in fatigue and exercise performance were observed at six

weeks however again not sustained at six-months post-intervention. Improvements in participant's anxiety levels and disease knowledge were statistically significant at 6 weeks and sustained at six months. As both anxiety and lack of disease knowledge are evidenced symptoms of COPD at the end of life (Gore, Brophy and Greenstone 2000), the results of this study are somewhat noteworthy when considering the use of self-management to improve coping for patients with COPD at this stage of disease progression. It is difficult to determine the degree of participant compliance as this was not measured throughout the study however the success of sustained improvements may suggest compliance was adequate alongside the co-creation of the intervention with people living with COPD who fully understand its impact upon daily life, strengthening the argument for understanding patient's perceptions when determining the effect of an intervention.

It is evident from the literature when evaluating the use of self-management within COPD that a positive impact upon symptom burden and patients' ability to cope is possible, yet is dependent upon the method of intervention delivery and intervention content. Results demonstrate variability of effect upon different symptoms. These studies have demonstrated some understanding of the overall efficacy of these interventions, however they do not assist in the appreciation of the perceptions of patients, their carers and healthcare professionals of the lived experiences when participating and how they believe the intervention has impacted upon them. This information is essential when determining the need for further work to explore the impact of self-management as a coping strategy for patients with COPD at the end of life as patient experience and preference are fundamental to any service design, particularly at such an important time in life. By understanding the perceptions of patients the discrepancies in palliative care provision for those with COPD may begin to be addressed by determining their views of managing their condition themselves at the end of life and how they wish to be supported through this. Patient perceptions will also assist in identification of barriers to implementation of self-management interventions and may produce suggestions to overcome these in order to assist with coping and potentially improve patient quality of life.

2.4 - The needs of patients with COPD at the end of life

The symptom burden and consequential needs of patients with advanced COPD at the end of life are evidenced and are able to be predicted, yet inadequacies in palliative care access remain when compared to lung cancer (Brown, Jecker and Curtis 2016).

The most frequently reported symptom, presenting the most significant impact is unsurprisingly breathlessness. Due to the nature of COPD disease progression, with lung function decline present over time, an increase in breathlessness symptoms is inevitable. Within a longitudinal observational study of 100 participants with advanced COPD (Blinderman et al. 2009) 94% of patients experienced breathlessness with over half of the study population labelling the symptom 'particularly distressful'. A study undertaking post- bereavement interviews demonstrated that greater than 90% of patients with COPD had increased breathlessness within the last year of life, with over half not responding to pharmacological treatment including oxygen therapy (Hasson et al. 2009). Further studies (Benzo et al. 2013, Habraken et al. 2007a, Spathis and Booth 2008), echo the significance of breathlessness for this cohort of patients and the impact it has upon other symptoms. Breathlessness is distressing and frightening as a physical symptom alone therefore it is unsurprising that links have been made between breathlessness and anxiety and depression (Hill et al. 2008).

A high prevalence of anxiety is evidenced within advanced COPD at the end of life (Blinderman et al. 2009, Habraken et al. 2007). A comparison study of symptoms of advanced COPD with lung cancer (Gore, Brophy and Greenstone 2000) identified that 90% of the 50 COPD participants had clinically significant anxiety or depression. This level of anxiety and depression is significantly greater than in earlier stages of COPD progression, with between 36 to 40% of patients attending pulmonary rehabilitation estimated as suffering from anxiety and depression (Harrison et al. 2011). This identifies the increased prevalence of specific needs of patients with COPD at the end of life, and the need for provision of

coping strategies to assist is of paramount importance. There are many possible causes of anxiety and depression for consideration alongside the link with breathlessness such as social isolation and fear of death (Gardiner et al. 2009, Habraken et al. 2007a). Despite anxiety often being identified, it is felt that the psychological needs of patients with advanced COPD are often given less focus than the physical needs (Habraken et al. 2007), however the effect of these psychological needs have the potential to significantly impact upon a person's daily life and eventually their physical abilities.

Fatigue and extreme tiredness has been identified as a symptom to cause distress (Blinderman et al. 2009, Disler et al. 2012), and it is suggested that disease related anxiety may contribute to this (Hill et al. 2008). The physical impact of breathlessness and associated work of breathing alongside the use of nervous energy allows fatigue to be easily developed.

Breathlessness, anxiety, low mood, fatigue, social isolation and pain have a major impact upon overall quality of life for patients with advanced COPD (Gore, Brophy and Greenstone 2000). Overall low quality of life scores are present within studies including this cohort of COPD patients (Blinderman et al. 2009, Habraken et al. 2007), an understandable outcome given the great symptomatic impact throughout disease progression towards the end of life. Furthermore, a need for information upon illness and disease trajectory is essential for patients with advanced COPD yet is evidently unmet within the literature. A study using semi- structured interviews of 21 patients with advanced COPD (Gardiner et al. 2009) acknowledges this and alarmingly demonstrates that 11 of the participants believed they had other conditions or were unaware of their cause of illness alongside the disease trajectory. This theme is supported within other studies (Gore, Brophy and Greenstone 2000, Habraken et al. 2007b) related to information upon prognosis and death.

Despite the evidence of predictable symptoms and disease specific needs, palliative care for patients with COPD remains poorly implemented (Benzo et al. 2013) yet it is believed that

palliative symptom management should commence alongside active treatment at any time throughout disease progression (Gore, Brophy and Greenstone 2000).

2.5 – Defining end of life in COPD

The classification of what constitutes end of life in COPD is fundamental to the understanding of the impact of a self-management intervention at this point in disease progression. Defining when a person is at the end of life is complex and requires multiple considerations bringing uncertainty and difficulty in determining prognosis due to the unpredictable trajectory of COPD (Spathis and Booth 2008).

As identified by the General Medical Council (2010), a high probability of death within the next twelve months suggests a person is nearing the end of life, however this prediction brings challenges without further understanding of disease specific prognostic indicators. Attempts have been made to facilitate this prediction including the Gold Standards Framework (2011), which suggest the use of three trigger questions (Table 1.0), to assist practitioners in assessment of when a patient is nearing the end of life. It is however acknowledged that despite the presence of such clinical indicators, giving a prognosis remains uncertain. The use of these trigger questions are however a basis from which to begin to understand the characteristics present within COPD at the end of life to formulate a clinical assessment and determine the requirement of palliative care.

The uncertain disease trajectory present within COPD disease progression makes categorisation within the criteria of Table 1.0 implausible for some as patients are often unwell for a number of months or years, with exacerbations occurring sporadically (presented within Figure 1.0). Each exacerbation may be the cause of death (Boyd et al. 2005), yet commonly patients do live throughout many exacerbations with ongoing deterioration in physical and social health requiring an intensive period of nursing and social support (Carlucci, Guerrieri and Nava 2012). Often, the death of a patient is deemed unexpected (Boyd et al. 2005), again reinforcing the difficulties with prognostication.

Table 1.0 – Triggers that suggest patients are nearing the end of life

(The Gold Standards Framework 2011)

Figure 1.0 – COPD Disease Trajectory © (Murray et al. 2005)

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A well-documented symptom throughout the COPD disease trajectory is the enhanced decline in lung function (Tantucci and Modina 2012) and the severity of spirometric abnormality has been termed within stages of disease progression (Global Initiative for Chronic Obstructive Lung Disease 2017), demonstrated within Table 2.0. Determining a patients' severity of airflow obstruction will not allow for determination of prognosis or the identification of deterioration in health status (Jones 2001), thus requiring symptomatic assessment to thoroughly determine prognosis.

Table 2.0 – GOLD COPD Stages of Disease Progression

(Global Initiative For Chronic Obstructive Lung Disease 2017)

Classification tools have been developed to acknowledge this, combining both lung function and health status assessment to assist practitioners with prognostication. The most frequently utilised tools are the GOLD assessment tool (Global Initiative for Chronic Obstructive Lung Disease 2017), and the body-mass index, airflow obstruction, dyspnoea and exercise (BODE) Index (Powrie 2004). The development of the BODE tool resulted from a study of the COPD symptoms and physical measures of 207 patients were evaluated to determine predictors to indicate death (Celli et al. 2004). The study concluded that four factors best predicted a COPD patient's prognosis, body mass index (BMI), their degree of airflow obstruction (post-bronchodilation FEV1), dyspnoea (measured using the mMRC score) and exercise tolerance, shown within Figure 2.0. Each factor is scored 0-3 (0-1) for BMI with a greater BODE Index score indicating a higher risk of death.

Figure 2.0 – BODE Index Tool (Todd et al. 2008)

Interestingly, the GOLD assessment tool considers different impact aspects of the disease (Figure 3.0), taking into account the exacerbation history of patients and the development of co-morbidities alongside current severity of symptoms when determining their risk of death.

Some materials have been removed from this thesis due to Third Party Copyright. The unabridged version of the thesis can be viewed at the Lanchester Library, Coventry University.

Figure 3.0 – GOLD refined ABCD Assessment Tool (Global Initiative for Chronic Obstructive Lung Disease 2017)

The symptomatic assessment and impact upon health status is again facilitated by an evidence-based tool, with the document referring to the use of the Modified British Medical Research Council (mMRC) dyspnoea scale (Fletcher 1952) and the COPD Assessment Test – CAT (Jones et al. 2009). The mMRC focuses upon that person's degree of breathlessness

when undertaking activities of daily living. Higher scores indicate a significant impact of symptoms upon health status. The CAT tool is designed to assess disease impact upon quality of life similarly with the highest scores indicating higher impact. The GOLD refined ABCD Assessment Tool, as presented within Figure 3.0 suggests those with a CAT score of greater than ten are at greater risk of exacerbations and symptom burden. For the purpose of defining the end of life in COPD within this systematic review, a CAT score of greater then 20 is considered to include patients at the end of life due to the score suggesting high or very high symptom impact which prevents patients undertaking daily tasks alongside feeling their condition is beyond their control. Both tools evaluate the symptomatic burden of COPD upon the individual giving a clinical picture of their current health and social status. Concurrent to this, within the GOLD assessment tool, spirometric function and symptom impact are also considered by categorising patients within groups A to D dependent upon symptomatic assessment and risk of exacerbations (demonstrated within figure 3.0). Group B identifies patients as having a low risk of exacerbations yet increased symptoms impacting upon health status and Group D suggesting patients have a high risk of exacerbations with significant symptoms affecting daily life. Linking this to the unpredictable disease trajectory of COPD and the knowledge of increased overwhelming symptoms present within very severe disease progression, these two group classifications would be appropriate to consider when a patient is nearing or at the end of life. Survival statistics are difficult to collate to determine at what stage of GOLD severity or BODE index score patients are when they die and such data remains unpublished.

Consideration has been given to each of the evidenced contributory components to determine when a patient with COPD is at the end of life and therefore, for the purpose of this systematic review, the definition of COPD at the end of life to be used is demonstrated within Figure 4.0. Patients must meet at least one of the criteria within both shaded boxes to be classified as being within the last twelve months of life.

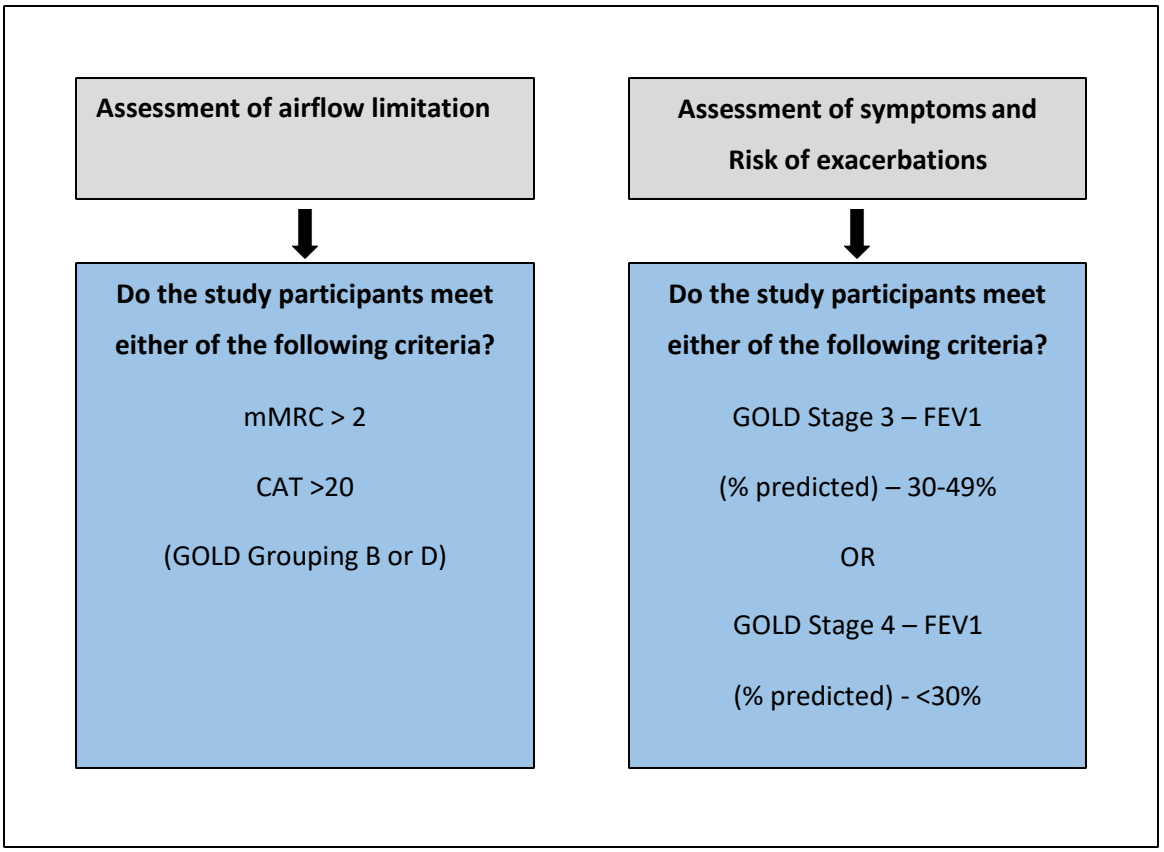

Figure 4.0 – Definition of COPD at the end of life

2.6 – Summary

COPD is a condition of irreversible airway damage resulting in breathlessness, increased sputum production, chronic cough and further co-morbidities including cardiac disease, diabetes mellitus, osteoporosis and psychological disorders. The impact of such symptoms results in reduced physical and social activity. COPD impacts not only upon the individual but also healthcare provision worldwide.

The unpredictable trajectory of the disease makes defining when a patient with COPD is at the end of life uncertain and may begin to explain inadequacies in palliative care provision for these patients. Attempts to determine when a patient with COPD is at the end of life can be made, however acknowledgement must be given to the chance of inaccurate prediction allowing for a period of life without adequate care or coping ability resulting in potential distress at a very sensitive time and the absence of choice around a persons end of life care.

The symptoms of COPD at the end of life are well-evidenced and are able to be predicted, allowing for measures to be implemented prior to this time to allow patients to cope with dignity and choice. These known symptoms have been successfully improved as a result of some self-management intervention studies of which some contain patients with COPD at the end of life, yet no work has been undertaken explicitly evaluating its impact at this point within disease progression. The variation of intervention components and methods of delivery make this evaluation difficult as studies labelled as self-management range from a leaflet giving brief disease information to prolonged periods of education, delivery, support and counselling (Borbeau 2003). Remarkably the studies delivering intensive education and support do not demonstrate results of increased behaviour change, with the most successful work in obtaining sustained behaviour change was a brief, patient-led intervention (Mitchell et al. 2014). The gold standard of self-management within COPD remains unclear.

The aim of this dissertation is to evaluate the use of self-management interventions as a coping strategy for patients with COPD at the end of life by exploring the perspectives of patients, carers and healthcare professionals. Existing studies evaluating the impact of self-management within COPD have included cohorts of patients defined (by using the definition explained within section 2.5) as being at the end of life. To enable understanding of the patients, carers and healthcare professional's perceptions of self-management interventions at the end of life from further analysis of existing studies, a qualitative systematic review of this literature will be undertaken to develop a new concept surrounding its use to improve end of life care for patients with COPD. The review will also aim to explore when in the COPD disease trajectory a self-management intervention is required to be implemented to have benefit when a patient with COPD is at the end of life.

Chapter 3.0 – Methodology and Underpinning Philosophy

This chapter outlines and critically evaluates the chosen research methodology and underpinning philosophy of this study. The chapter is divided into two sections. Firstly, the research methodology will be explored (section 3.1) giving a rationale for the chosen approach to answering the research question proposed within this thesis. Section 3.2 will focus upon the underpinning philosophy of the study to further justify the chosen methods of exploration to meet the aims of understanding the perceptions of patients, carers and healthcare professionals upon the use of self-management as a coping strategy at the end of life.

3.1 - Methodology

The undertaking of a systematic review to answer the aim and objectives of this thesis is the most suitable approach, allowing a rigorous exploration of existing literature to then synthesise and develop new concepts (Mulrow 1994) surrounding the use of self- management as a coping strategy for people with advanced COPD at the end of life.

Clinical practice within healthcare is underpinned by best available evidence and the requirement for this to be of the highest, most reliable standard is paramount. The rigorous structure of a systematic review leads to its interpretation as being evidence at the hierarchical pinnacle of research methods when evaluating the impact of interventions (Akobeng 2005), yet this remains dependent upon the methodological quality of studies within the review (Cochrane Library 2016). Systematic reviews prescribe that the quality of included research is appraised, using clear pre-defined criteria to develop valid and reliable results (Bryman 2016), therefore avoiding selection of studies to be included or excluded to influence findings. Weight is given to conclusions made, based upon the quality of each included study. This contrasts with features of a narrative review, that has limitations with reproducibility due to the absence of pre-determined inclusion and exclusion criteria, allowing selection of literature to provide wanted views, reducing its scientific reliability (Rumrill and Fitzgerald 2001).

To investigate and understand the perceptions of patients, carers and healthcare professionals in relation to self-management interventions at the end of life, a critical appraisal and subsequent synthesis of studies utilising a qualitative research methodology is most appropriate to unfold an understanding of how participants put into context their world and lived experiences (Merriam 2009). Qualitative, meaning ‘to be measured by quality’ (Oxford English Dictionary, 2018) allows for the exploration of the personally understood value of an experience through spoken and written words to develop reflective and significant data to fully explore lived experiences. Such a rich form of data capturing the experiences

and impact upon thoughts and feelings would not be achieved through undertaking an analysis of quantitative studies due to the primary aim being to demonstrate the effect through numerical presentation and statistical significance to display a common truth (Egger, Smith and Phillips 1997). Quantitative studies do not allow for the further exploration of the personal meaning and understanding of that impact, thus the analytical method adopted for use when interpreting qualitative data is paramount to gain the results required to develop that understanding.

Qualitative data analysis is approached through varying methods dependent upon the desired outcome to answer the research question. One approach to reviewing qualitative research findings is a narrative synthesis, a process of telling the story behind the findings of all included studies (Rodgers et al. 2009) through a systematic approach to develop a theory of how something works, the rationale behind its success and whom the impact will affect (Popay et al. 2006). When undertaking a systematic review, sensitivity analysis of results from included studies is essential to maintain the rigor of the study and reliability of results through any uncertainty identified within a study's inputs, for example missing data being acknowledged within the synthesis findings to satisfy confidence within the conclusions (Saltelli 2002). A narrative synthesis does not allow for this making it an unsuitable analytical method for a true systematic review and for use within this thesis.

The use of meta-analytical approaches within qualitative data analysis is becoming increasingly common within healthcare research and was initially utilised by Stern and Harris (1985), with further influential work and theory development being published by Noblit and Hare (1988). The concept of a meta-analysis of qualitative data is to develop a succinct and inclusive portrayal of findings through a number of qualitative studies upon the same subject of research (Timulak 2009) to provide a new clarification of findings more substantial than those studies in isolation (Finfgeld 2003), changing those findings into new concepts (Schreiber, Crooks and Stern 1997). The overarching aim of a qualitative meta-analysis is to further contribute to knowledge within a chosen field (Timulak 2009).

Limitations of qualitative meta-analytical approaches are linked to a possible loss of sensitivity to the original meaning of data, due to this approach not usually accessing the raw data from each study (Paterson 2001), therefore requiring the researcher to interpret the context of each study and participants' responses alongside their given responses as data for analysis (Timulak 2009). One meta-analytical approach considering these sensitivities within the analytical structure is the process of meta-ethnography (Noblit and Hare 1988).

The theory of meta-ethnography is when the interpretation of qualitative data is explanatory and not merely data collaborated into a whole, with the process of translation of studies into each other being to develop correlations between accounts whilst still maintaining their original meaning (Noblit and Hare 1988). This will allow for the process being a logical method of providing strong evidence for a truthful conclusion. As a systematic approach to qualitative data analysis, meta-ethnography is constructed of seven steps to data analysis, demonstrated within Table 3.0. The use of these seven steps within this thesis will be further explained within Section 4.10 of Chapter 4.0 giving an explanation of the practical application of each phase.

Table 3.0 - The Seven Steps of Meta-ethnography

(Noblit and Hare 1988)

The use of meta-ethnography was decided upon as the most appropriate analytical method to underpin this systematic review. The area of initial interest being improvement of coping strategies for patients with COPD at the end of life would be most effectively answered by qualitative means to determine, from the views of the patients themselves alongside their carers and specialised healthcare professionals exactly what will assist them to cope. There is a plethora of qualitative research studies exploring the use of self-management within COPD, in which many have included cohorts of patients whom are at the end of life. This systematic review enables these studies to be analysed and metaphoric extraction undertaken to develop a new concept to determine if advocating patient self-management is an acceptable coping strategy to assist with overwhelming symptom burden for patients with COPD at the end of life.

3.2 – Underpinning Research Philosophy

The inductive approach of meta-ethnography, with a view of generating new concepts from existing research (Bryman 2016), is underpinned by an interpretivist epistemological position utilising the theory that individuals perceive and understand the same 'social reality' independently adopting their own views to develop new knowledge (Crotty 2003). This differs from a positivist epistemological position of trusting the existing presence of the social world allowing a detached approach when exploring social relationships to discover a single underlying truth (Denscombe 2014). This study does not aim to determine a single underlying truth, yet aims to distinguish how social interactions, the development and growth of relationships and the acquisition of knowledge effect symptom burden for patients living with advanced COPD through the systematic interrogation of pre-existing studies. Underpinning the researchers' interpretation of how subjects relate to each other is the ontological position of constructivism, whereby social interaction develops the social objects of a person's perception such as the development of new behaviours (Bryman 2016). This is of particular significance within this systematic review when aiming to understand how certain components of self-management interventions impact upon individuals.

Chapter 4.0 – Research Methods

The aim of this chapter is to present the chosen research methods to effectively determine the effect of self-management as a coping strategy for patients with COPD at the end of life. The chapter is divided into 12 sections exploring the process of undertaking a systematic review. Section 4.1 gives the rationale for using a systematic review approach to synthesise existing research studies to create findings to influence the future care of patients with COPD at the end of life. Section 4.2 describes the development of a systematic review protocol, with section 4.3 explaining the ethical considerations made within this study.

Section 4.4 displays the pre-defined eligibility criteria and its rationale for studies to be included within the review. The database search strategy is explained within section 4.6 and a subsequent description of data management is given (4.7). The study selection process is presented within section 4.8 with a description of the 25 included studies within this systematic review. Data collected from each included study is given within section 4.9 and the potential risk of bias is discussed within section 4.10.

The process of data synthesis through the reciprocal translation of studies is given throughout section 4.11 and is further analysed to determine the confidence in cumulative estimate when used within the study's findings (section 4.12).

4.1 – Systematic Review Methods Framework

There are several established frameworks available for use when designing the structure of a systematic review, with the purpose of discouraging selective reporting at each stage within the process being clearly defined and explained (Shamseer et al. 2015). The Cochrane Collaboration (2017), are regarded as the organisation who deliver systematic reviews of the highest standard worldwide, developed the handbook for systematic reviews of interventions. This handbook outlines the expected components required to be included within a systematic review however there is little available evidence of how this handbook was constructed and the components agreed as content. The Joanna Briggs Institute endorses the use of the 'Preferred Reporting Items for Systematic Review and Meta-Analysis protocols (PRISMA-P) checklist (Shamseer et al. 2015), outlining the expected components within a systematic review to ensure reliability and rigor whilst minimising bias to produce high quality research conclusions. The PRISMA-P checklist was formulated upon components of the International Prospective Register of Systematic Reviews (PROSPERO) register led by the centre for reviews and dissemination within the UK. This register allows for systematic review protocols to be registered to ensure duplication of reviews on the same topic reduces, alongside a transparent review process. Other systematic review guidelines were consulted within the formulation of PRISMA-P including Standard Protocol Items: Recommendations for Intervention trials (Chan et al. 2013) and the Institute of Medicine's standards for systematic reviews (Institute of Medicine 2011). An international consensus meeting was held to finalise the components of the PRISMA-P checklist giving the document a sound evidence base from which to use. The previously mentioned alternative checklists do not offer this assurance.

The PRISMA-P checklist has been chosen to structure the formation of a review protocol and the systematic review within this thesis for the rationale previously described alongside its advertised use when developing a systematic review protocol to evaluate the potential worth

of an intervention (Shamseer et al. 2015), lending itself to the aim and objectives of this thesis.

The PRISMA-P checklist compliments the underpinning meta-ethnographical theory by its requirement of a research question that is answerable through the identification of multiple studies, linking the checklist to step one of the seven steps of meta-ethnography (Noblit and Hare 1988). The checklist also requires the identification of studies for inclusion prior to undertaking analysis to allow for a true and transparent representation of new concepts.

4.2 – Systematic Review Protocol

A systematic review protocol was developed utilising the PRISMA-P Checklist (Shamseer et al. 2015), to ensure transparency of the study was maintained alongside the minimisation of bias. By publishing a systematic review protocol, it is then less likely studies will be included or excluded outside of the pre-determined criteria alongside the duplication of studies. The final protocol can be found within Appendix C.

This systematic review protocol, in accordance with the PRISMA-P guidelines has been registered with PROSPERO on December 2017 and amended on 26th February 2018 (Registration Number: CRD42017083741). The components of this systematic review protocol will be further discussed throughout this chapter throughout sections 4.4 to 4.12.

4.3 – Ethics and Governance

Ethical consideration and good practice when undertaking and publishing a systematic review is paramount to maintain transparency (Wager and Wiffen 2011), therefore upon completion of the systematic review protocol, an application was made to Coventry University Ethics and governance procedures to ensure the study met the expected ethical standards set by the university. As the systematic review contains the analysis secondary data, the ethical process ensures the study is robust and transparent in design to ensure that the tailoring of results to suit a desired outcome is not possible allowing the review to be a true representation of the data from included studies (Wager and Wiffen 2011). Ethical approval for the systematic review also intends to minimise research misconduct, maintaining the integrity of the host institution alongside ensuring all contributing authors are acknowledged within the application to facilitate good ethical practice (Committee on Publication Ethics 2011).

Ethical approval for this systematic review was obtained on 10th January 2018. The data search process commenced on 15th January 2018 following the receipt of ethical approval. The certificate of ethical approval can be found upon page ii of this dissertation (Approval reference Number: P62130).

4.4 – Eligibility Criteria

The development of inclusion and exclusion criteria to determine the studies for inclusion within this systematic review were formulated by utilising the PICO components of the research question to be answered (demonstrated within Table 4.0). This enabled the eligibility criteria to fully encompass all relevant parts of the research question using a structured approach, known to be a unique and important component of a systematic review (Higgins 2011). Displaying this information at the protocol stage of a systematic review is required to allow a transparent presentation of the reviews quality, relevance and scope (Counsell 1997).

The study eligibility criteria are displayed within table 4.0 with the rationale for each criterion explained. The review eligibility criteria are displayed within table 5.0 with the rationale given to explain each element.

Table 4.0 - Study Inclusion and Exclusion Criteria

	Inclusion Criteria	Rationale	Exclusion Criteria	Rationale
Population	Studies including participants over 40 years old with a diagnosis of COPD at GOLD Stage 3 or 4/CAT Score of greater than 20/ Group B or D	Based upon the definition used within this systematic review discussed within Chapter 2.0 - Section 2.1.	Studies including participants with a diagnosis of COPD at an earlier stage in disease progression (GOLD Stage 1 or 2/CAT Score of less than 20/mMRC>20/Group A or C)	Studies including participants meeting this criterion do not comply with the definition of COPD at the end of life given within Chapter 2.0 – Section 2.1.
	Studies including participants with advanced COPD of mixed age groups if the results of above and below 40 years old are separated.	A diagnosis of COPD is most commonly for people over the age of 40 increasing significantly with age (British Lung Foundation 2016).	Studies including participants with a diagnosis of another chronic disease alongside COPD	The diagnosis of a secondary chronic disease may impact upon individuals coping abilities therefore could introduce false interpretation of results.

	Inclusion Criteria	Rationale	Exclusion Criteria	Rationale
Population	Studies including participants of either gender.	COPD affects people of either gender therefore no exclusion is required on this basis.	Studies including participants under 30 years of age.	A diagnosis of COPD is most commonly for people over the age of 40 increasing significantly with age (British Lung Foundation 2016).
	Studies including healthcare professionals of any profession (eg. Nurse, Doctor, Allied Health Professional), who have cared for patients meeting the end of life COPD criteria for a minimum of 2 years	Experience of caring for patients with COPD for a minimum of 2 years allows for the development of specialist knowledge in that field and is the requirement given in job descriptions for specialist disease related roles within healthcare.		

	Inclusion Criteria	Rationale	Exclusion Criteria	Rationale
Population	Studies including carers of any description (e.g. Family members, paid carers	Understanding the perceptions of carers will not be limited by their professional or informal capacity.		
	Patient groups that have a diagnosis of COPD at GOLD stage 3 or 4 (Groups B or D) with a mMRC of greater than 2 or CAT score of greater than 20 who have participated in a self-management intervention study.	Participants with these specified baseline demographics would meet the definition of COPD at the end of life explained within Chapter 2.0 – Section 2.1 alongside having participated within a self-management intervention.		

	Inclusion Criteria	Rationale	Exclusion Criteria	Rationale
Intervention	The self-management intervention must include one or more of the following components: • Decision-making techniques • Symptom monitoring skills • Action planning and Goal setting • Emotional management techniques • Problem solving techniques Continued.	Based upon the definition of a self-management intervention explained within Chapter 2.0- Section 2.3.	The self-management intervention exclusively includes components outside of the list given within the inclusion criteria.	Such self-management intervention components do not meet the given definition of self-management explained within Chapter 2.0 – Section 2.3

	Inclusion Criteria	Rationale	Exclusion Criteria	Rationale
Intervention	• Increased participant confidence • Action planning and goal setting • Behavioural-change techniques • Exacerbation management techniques • New knowledge component • Practicing new behaviours			

Table 5.0 – Review Eligibility Criteria

	Inclusion Criteria	Rationale
Study Type	Studies containing any type of qualitative data (e.g. Interviews, focus groups, workshops) Exploratory studies Randomised controlled trials containing a qualitative element of data collection Intervention studies Single case studies Systematic and other literature reviews PhD Theses	The systematic review question focuses upon the analysis of qualitative studies to address the proposed research aims as discussed within Chapter 3.0- Section 3.1.

	Inclusion Criteria	Rationale
Timing	Studies published prior to 1990 will be excluded.	There is little evidence of studies relating to the specified area of study within this thesis prior to this date.
Setting	There will be no restriction upon the setting of intervention delivery.	All setting types are required to be included to allow for an understanding of any environmental impact upon patient perception and behaviour change.
Language	English or American English languages	To maintain the accuracy of interpretation of results. The use of language translation tools may reduce the rigor of the study due to the increased potential of interpretative error.
Publication Status	Only studies that have been published into the public domain will be included.	To avoid the inclusion of preliminary findings that are yet to be finalised. By including such findings, conclusions could be falsely impacted. Conference papers and abstracts are excluded due to the potential of presenting preliminary findings and possible the absence of peer review.

4.5 – Information Sources

The literature search strategies were developed using subject headings and text words related to COPD, self-management and end of life care. These will be further discussed within section 4.6 of this chapter.

The searching of electronic bibliographic databases was undertaken as demonstrated within Table 6.0. By searching such an exhaustive list of databases assurance was gained that entire coverage of the subject area had been obtained acknowledging the potential variations between search results from each database (Shamseer et al. 2015). The choice of databases to include was made in collaboration with a specialist health studies librarian to allow for understanding of the most appropriate data sources for inclusion. The reference list from each study fitting the pre-defined inclusion criteria was scanned to identify potential studies for consideration allowing identification of all relevant literature (Horsley, Dingwall and Sampson 2011).

The data search began on 15th January 2018 and the final data search took place on Monday 25th April 2018 to allow for time to include any potential results within data analysis prior to the submission of this thesis. It is however acknowledged that a review of literature remains ongoing to allow for the consideration of new research developments, therefore future revisions of this systematic review will be made to ensure the reflection of all studies meeting the inclusion and exclusion criteria.

Table 6.0 – Searching of electronic bibliographic databases

Name of Source	Date Range Searched	Frequency of Search	Search Platform	Performed by
Academic Search Complete	15th January 2018 to 25th April 2018	Weekly	EBSCOhost	Louise Bolton
AMED	15th January 2018 to 25th April 2018	Weekly	EBSCOhost	Louise Bolton
CINHAL	15th January 2018 to 25th April 2018	Weekly	EBSCOhost	Louise Bolton
Family Health Database	15th January 2018 to 25th April 2018	Weekly	ProQUEST	Louise Bolton
Medline	15th January 2018 to 25th April 2018	Weekly	EBSCOhost	Louise Bolton
Psychology	15th January 2018 to 25th April 2018	Weekly	ProQUEST	Louise Bolton
PsychINFO	15th January 2018 to 25th April 2018	Weekly	EBSCOhost	Louise Bolton
SCOPUS	15th January 2018 to 25th April 2018	Weekly	SCOPUS Review	Louise Bolton

Name of Source	Date Range Searched	Frequency of Search	Search Platform	Performed by
PROSPERO Register of Systematic Reviews	15th January 2018 to 25th April 2018	Monthly	PROSPERO Database	Louise Bolton
Cochrane Database	15th January 2018 to 25th April 2018	Monthly	Cochrane Database	Louise Bolton
Ethos Thesis Database	15th January 2018 to 25th April 2018	Monthly	Ethos	Louise Bolton
Nursing and Allied Health Source	15th January 2018 to 25th April 2018	Monthly	ProQUEST	Louise Bolton

4.6 – Search Strategy

An extensive and high quality search strategy within a systematic review is an essential component to ensure an accurate and widespread representation of the published literature (McGowan, Sampson and Lefebvre 2010). The development of search terms for this systematic review was undertaken by the researcher and peer reviewed by the supervisory team to ensure the search terms remained focused upon the required subjects. To ensure each component of the research question would be reflected within the search terms, the PICO construction of the research question was used to formulate search terms into three groupings, COPD, self-management and end of life care. The list of database search terms used within each grouping are shown in Table 7.0. The search terms and syntax used for each individual database is displayed within Appendix G. Test searches were undertaken to determine all possible synonyms and variations within subject headings following training from a specialist health studies librarian.

Table 7.0 – Database Search Terms

	COPD	**Self-management**	**End of Life care**
Search Terms	COPD Respiratory Disease Emphysema Long-term conditions Respiratory conditions COPD Management COPD treatment COPD interventions	Self-management self- management Self-care/ self care *self-car* Symptom monitoring Symptom Goal setting Emotional management Emotion	Death Dying Dies Died Palliative care Palliative End of life Life end Terminal

	COPD	Self-management	End of Life care
Search Terms	COPD exacerbation Pulmonary disease	Anxiety management Problem solving Confidence Action plan/ Action-plan Behavioural change Behaviour change Exacerbation management Resilience Emotional *behav* Self-efficacy/self efficacy Empower Training/ *train* Decision-making/Decision Techniques New knowledge New behaviours Behaviour	

Terms from each grouping were initially searched individually then results combined using 'OR' to encompass all results within that subject grouping making an attempt to remove duplications. A display of this search method for the COPD search terms is demonstrated within Figure 5.0. This was undertaken for each of the three groupings before an overall 3 term search was completed using 'AND' as demonstrated within figure 5.0.

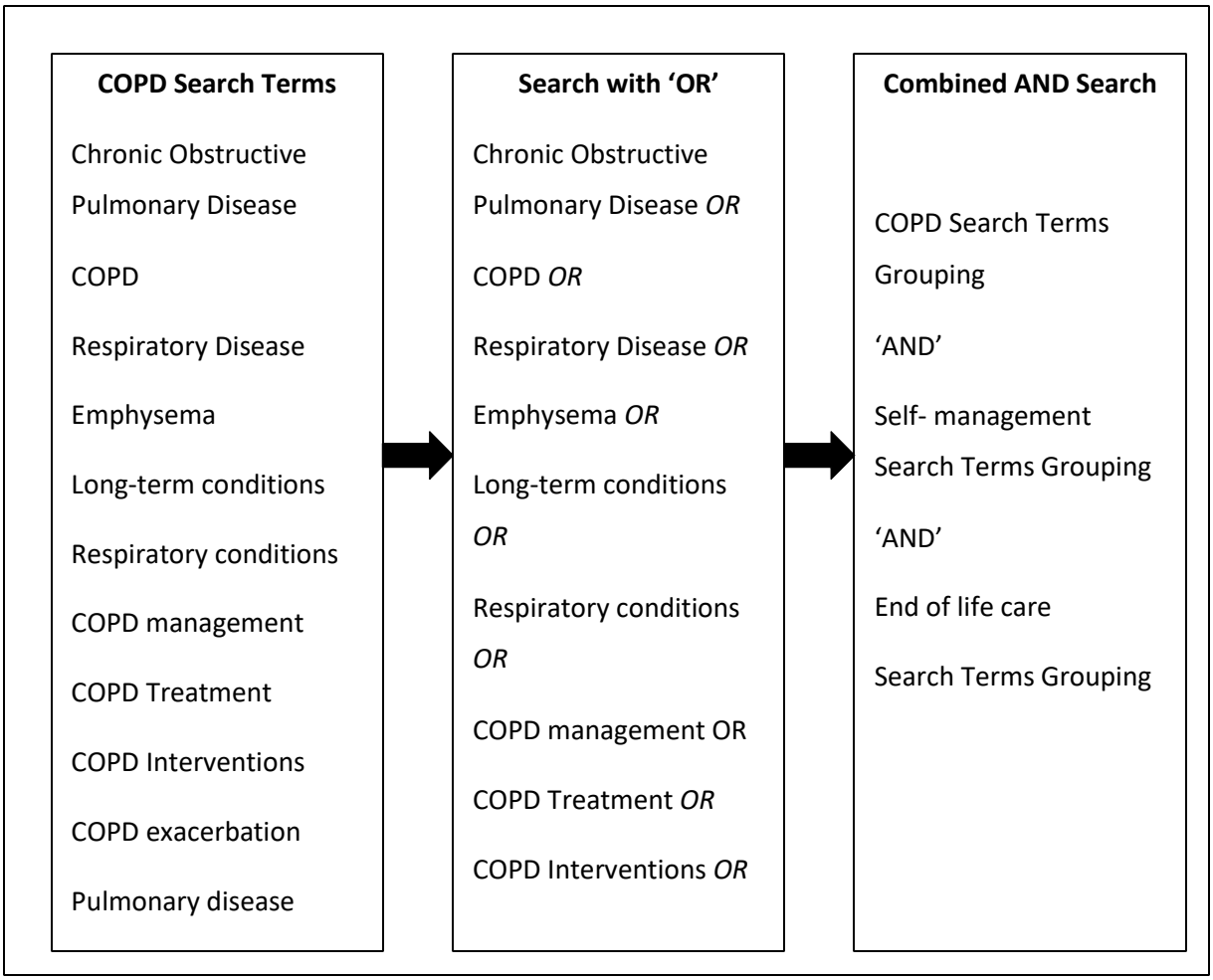

Figure 5.0 – COPD Search Terms Method

Due to the complexity of the research question within this thesis requiring there to be three subject groups, initial search results of all three groups searched with 'AND' eliminated a vast number of self-management studies relating to COPD due to the end of life component having not been explicitly researched, yet studies upon the use of self-management within COPD have included participants meeting the definition of COPD at the end of life given in

chapter 2.0 –Section 2.1, therefore were eligible for inclusion within this systematic review. To overcome this exclusion of potentially eligible studies from the evidence base, each database was searched twice, firstly a three term search using all three search term groupings as demonstrated within figure 5.0, and secondly a two term search with only the COPD search terms grouping and the self-management search terms grouping. Results from the two term search then had to be manually full-text screened using participants' baseline demographics to allow for the application of the inclusion criteria. A further explanation of this process is discussed within section 4.8 of this chapter.

4.7 - Data Management

Within the systematic review protocol, the use of Distiller SR software, an online software program allowing the upload of literature and the collaboration of reviewers when screening articles had been stated as the data management process. Due to the nature of the Distiller SR subscription policy not allowing the collaboration features with the university student account creation, this was unable to be used. Therefore, a more traditional method was adopted of a three phase results database created via Microsoft Excel.

The phase one database held the initial 802 search results following title and abstract screening. These results were manually inputted by the researcher and corresponding studies saved upon external hardware for future reference. A sample of the phase one database is displayed within figure 6.0. This database allowed for a display of the search result number, database of origin, study author and study title. Menu options were then given to allow the reviewer to select how each study met the inclusion or exclusion criteria. Further discussion upon the study selection processes and application of the inclusion and exclusion criteria is presented within section 4.8 of this chapter.

From the results, 122 contained qualitative data requiring further inclusion screening from the phase one database were then copied into the phase two database to provide a record of the data extraction process as demonstrated within Figure 7.0.

These results were then equally divided amongst the review team creating four phase 3 databases to allow for independent review when applying the study inclusion and exclusion criteria. The phase three database gave the reviewer options from which to select to demonstrate study inclusion or exclusion based upon the pre-defined criteria as displayed within Figure 8.0. The studies identified for inclusion within this systematic review are recorded upon the phase three databases.

Database of Origin	Result No	Study Title	Lead Author	Other database of origin	Inclusion/Exclusion Criteria
AMED	35	Factors affecting self-care	Parks 2017		Duplicate
AMED	4	Development of Integrated	Sunde 2014	SCOPUS	Duplicate
AMED	37	Development of a national SM	Mullaney 2016	CINHAL/ASC	Not COPD
AMED	9	Pul Rehab - EOL	Bennett 2016	CINHAL	Not empirical
AMED	51	Palliative care for COPD	Choudhuri 2012		Not empirical
AMED	411	Self care 21st century	Colin 2009		Not empirical

Figure 6.0 – Phase one database

Database of Origin	Result No	Study Title	Lead Author	Data collection Type
FHD	6	Development & Polit Testing	Apps 2013	Qualitative
SCOPUS	784	How do informal	Apps 2014	Qualitative
FHD	17	SPACE FOR COPD	Apps 2017	Qualitative
FHD	111	Deploying telehealth	Bailey 2015	Qualitative
NAH	243	Case study	Barnes 2009	Qualitative
ASC	42	Efficacy and Safety	Barnstein-Fonseca 2011	Qualitative

Figure 7.0 – Phase two database

Origin Database	Result No	Title	Authour	Second Reviewer	End of Life COPD Criteria Met?	Self-management criteria met?	Healthcare Professional Criteria Met?	Carers Criteria Met?	Include/Exclude	Comments
FHD	6	Development & Polit Testing	Apps 2013	[redacted]	Yes	Yes			Include	Group 1 in Qual Study - FEV1 22.6% Predicted
SCOPUS	784	How do informal	Apps 2014	[redacted]	Yes	Yes	N/A	N/A	Include	
		SPACE FOR	Apps							Participants lowest FEV1 31.8%

Figure 8.0 – Phase three database

4.8 – Study selection processes

Following the initial database searches as described within section 4.5, 1, 253, 857 search results were initially title screened by the lead researcher. The reason for the extremely high number of initial search results was due to the application of the 'long-term conditions' search term retrieving 726,569 non-COPD related results as shown within figure 9.0 demonstrating the overall study selection process of this systematic review. This search term was however required as some results relevant to the inclusion criteria would not have been identified outside of the use of this search term due to the lack of COPD within the study title.

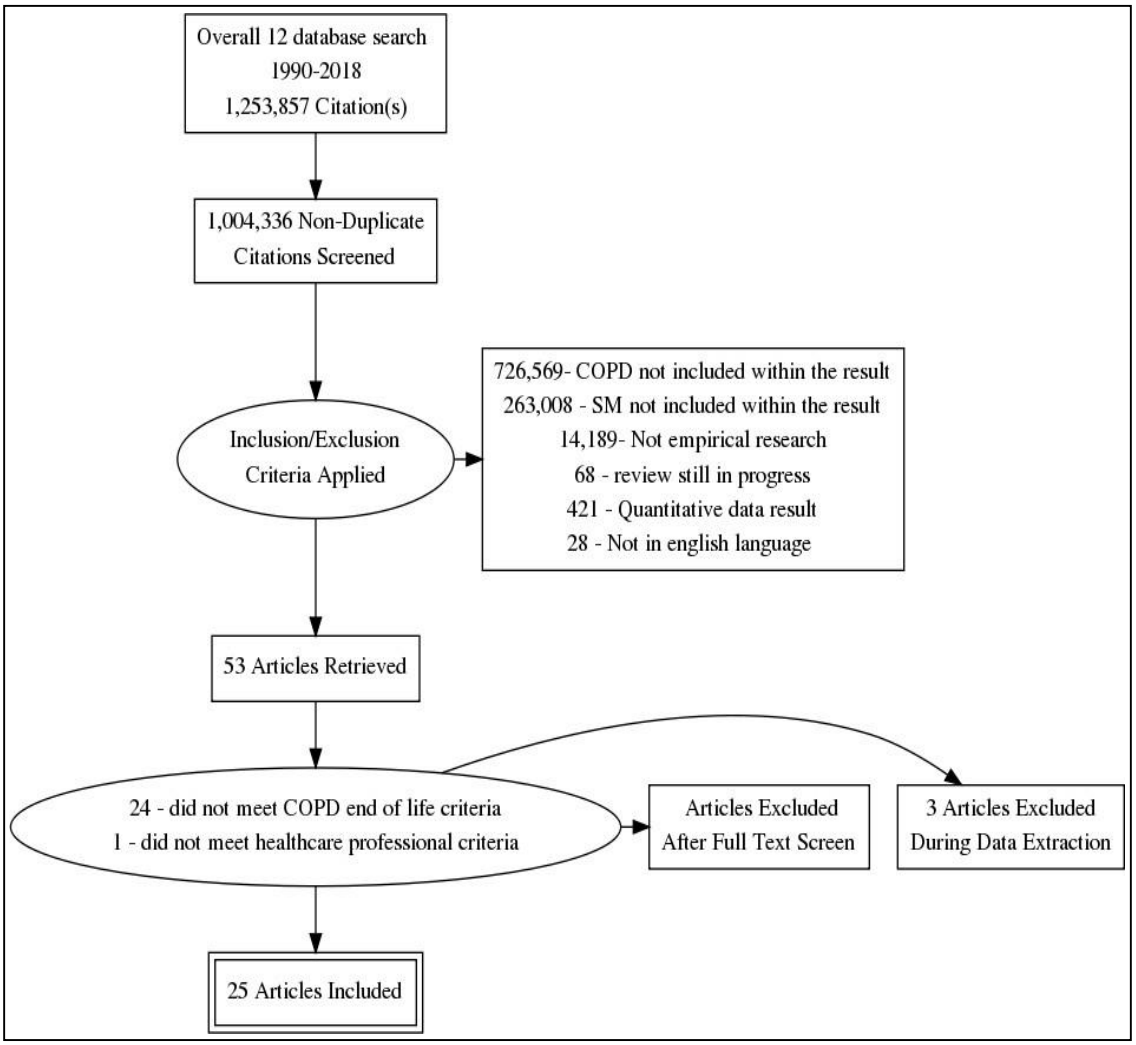

Figure 9.0 – Overall Database search results

When unable to identify the study content from the title, the abstract was screened to determine eligibility for further inclusion consideration. The individual database search results are demonstrated within Table 8.0. The removal of duplication results reduced the number of papers for further review to 1,004,336 as shown within figure 9.0.

Table 8.0 – Individual Database search results

Database	Two term search	Three term search
Academic Search Complete	279, 834	314
AMED	2614	389
CINHAL	142	8099
Family Health Database	629	139,005
Medline	569	12, 237
Psychology	238, 560	
PsychINFO	72	3
SCOPUS	235, 431	32, 578
PROSPERO Register of Systematic Reviews	72	
Cochrane Database	83	
Ethos Thesis Database	92	
Nursing and Allied Health Source	303, 206	

The application of initial inclusion and exclusion criteria were conducted in stages to allow for exclusion to be undertaken using a systematic approach. Firstly, 726,569 results without COPD within the study were removed by title and abstract screening as shown within figure 9.0. 28 results were excluded due to them not being written in the English language as identified within the exclusion criteria displayed in table 5.0. A further 263, 017 results were excluded at this stage as the study did not include any element of self-management or behaviour change within the study. 14, 189 results were excluded due to them not being empirical research studies and included such literature as letters to the editor and miscellaneous article abstracts without references. 68 results, mainly systematic reviews were excluded at this stage due the review still being in progress. The second phase of exclusion resulted in the removal of all studies with purely quantitative data within the study methods, excluding a further 446 studies, leaving results for full text screening within the third stage. The third stage of exclusion was undertaken by two reviewers to apply the detailed inclusion and exclusion criteria outlined within table 4.0 through reading of the full text. Each member of the reviewing team received training upon the application of the inclusions and exclusion criteria. The remaining 64 results were all screened by the lead researcher and independently second screened by another member of the supervisory team or independent researcher. This third stage resulted in the exclusion of 24 results not meeting the end of life COPD criteria, 9 results not meeting the self-management criteria and one result not meeting the healthcare professional criteria, therefore leaving 25 results for inclusion within the systematic review. The papers for inclusion within the systematic review are presented within table 9.0.

Table 9.0 – Studies for inclusion within the systematic review

Number	Author and Date	Study Title
1	Monninkhof (2004)	A qualitative evaluation of a comprehensive self-management programme for COPD patients: effectiveness from the patients perspective
2	Robinson et al. (2008)	Transforming clinical practice amongst community nurses: mentoring for COPD patient self-management
3	Reinke et al. (2011)	Feasibility of a Webinar for coaching patients with chronic obstructive pulmonary disease on end of life communication
4	Wang et al. (2012)	Patients with acute exacerbation of chronic obstructive pulmonary disease feel safe when treated at home: a qualitative study
5	Apps et al. (2013)	The development and pilot testing of the self-management programme of Activity, Coping and Education for Chronic Obstructive Pulmonary Disease (SPACE for COPD)
6	Benzo et al. (2013)	Development and Feasibility of a COPD self-management intervention delivered with motivational interviewing strategies
7	Benzo (2013)	Mindfulness and Motivational Interviewing: Two candidate methods for promoting self-management

Number	Author and Date	Study Title
8	Kennedy et al. (2013)	Implementing, embedding and integrating self-management support tools for people with long-term conditions in primary care nursing: a qualitative study
9	Meis et al. 2013	A qualitative assessment of COPD patients'' experiences of pulmonary rehabilitation and guidance by healthcare professionals
10	Simpson and Jones (2013)	An exploration of self-efficacy and self-management in COPD patients
11	Davies et al. (2014)	Primary and secondary care clinicians' views on self-treatment of COPD exacerbations: A multinational qualitative study
12	Sohanpal (2014)	Understanding the reasons for non-participation in self-management interventions amongst patients with chronic conditions: addressing and increasing opportunities for patients with advanced chronic obstructive pulmonary disease to access self-management
14	Buckingham et al. (2014)	HELPing older people with very severe chronic obstructive pulmonary disease (HELP-COPD): mixed-method feasibility pilot randomised controlled trial of a novel intervention

Number	Author and Date	Study Title
15	Burkow (2013)	Internet-enabled pulmonary rehabilitation and diabetes education in group settings at home: a preliminary study of patient acceptability
16	MacNab (2015)	Oximetry-supported self-management for chronic obstructive pulmonary disease: mixed methods feasibility pilot project
17	Mathar (2015)	A qualitative study of televideo consultations for COPD patients
18	Young et al. (2015)	Important, misunderstood, and challenging: a qualitative study of nurses' and allied health professionals' perceptions of implementing self-management for patients with COPD
19	Chen (2016)	Living with chronic obstructive pulmonary disease: The process of self-managing chronic obstructive pulmonary disease
20	Harrison et al. (2016)	Perspectives of healthcare professionals and patients on the application of mindfulness in individuals with chronic obstructive pulmonary disease
21	Blackmore et al. (2017)	Development of a training program to support health care professionals to deliver the SPACE for COPD self-management program

Number	Author and Date	Study Title
22	Bove et al. (2017)	Home-based psychoeducation: A qualitative study of the patients' experiences
23	Early (2017)	A case series of an off-the-shelf online health resource with integrated nurse coaching to support self-management in COPD
24	Nissen and Lindhardt (2017)	A qualitative study of COPD patients' experience of a telemedicine intervention
25	Russell et al. (2017)	Qualitative systematic review of barriers and facilitators to self-management of chronic obstructive pulmonary disease: views of patients and healthcare professionals

4.9 – Data collection process

Throughout the initial reading of the 25 included studies within this systematic review, demographic study data was extracted using an adapted version of the Critical Appraisal Skills Programme tool – CASP (2017). This particular study appraisal tool was selected due to its ability to be adapted to encompass the underpinning meta-ethnographical approach to data analysis, specifically around maintaining the original meaning of the studies by identifying presented themes and results from the beginning of data analysis (Noblit and Hare 1988). Alternative study appraisal tools have been considered and appraised for use within this study as demonstrated within table 10.

Table 10.0 – Study Data Extraction and Appraisal Tools

Appraisal Tool	Positive	Negative
Critical Appraisal Skills Programme (2017)	Ability to adapt to use with both qualitative and intervention studies.	Not designed to be used with mixed methods research.
Centre for Evidence Based Medicine (2005)	Clear and focussed questions to systematically appraise a study.	No provision of a tool for qualitative data analysis.
CONSORT (2010)	Comprehensive and systematic reporting tool with components related to the validity and reliability of included studies.	Designed for use with Randomised Controlled Trials. Unable to be adapted.
Tong, Sainsbury and Craig (2007)	Systematic tool for appraisal of qualitative research.	Does not allow for inclusion of intervention study appraisal.

The full proforma document used within this study is displayed within Appendix E. A pilot data extraction exercise was undertaken with four of the included papers to determine its usability and from this the tool required no further adaptation. This process was undertaken by the lead researcher as the degree of reviewer experience has not been identified as a potential for extraction error (Horton et al. 2010).

Relevant data extracted to display the features from each included study is displayed within table 11 and has been used to determine the confidence in cumulative estimate that is further explained within section 4.12. Demographic data from each study was extracted to contextualise the results including the intervention delivery, data collection and analysis alongside the preservation of each studies original themes throughout the meta-ethnographical analysis.

Table 11.0 - Features of the included 25 studies

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
1. Monninkhof et al. (2003)	Netherlands	Patients with a COPD diagnosis Age (mean) $\pm SD$) 66$\pm$ 18 FEV¹ (% predicted) 55 $\pm$ 18	Self-management programme: Information booklet and education course (5 2-hour group sessions) Fitness programme (1 or 2 1-hour) small group training session weekly Guidelines for self-treatment of exacerbations of COPD	20 participants: 10 Male/ 10 Female	In-depth, semi-structured interviews	Principles of grounded theory through coding of qualitative data	None identified. No conflicts of interest.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
2. Robinson et al. (2008)	Australia	Community health nurses (CHN's) 20 Female/ 1 Male All with a minimum community nursing experience between 1->10 years.	Education for CHN's consisted of a workshop based upon the transtheortetical model of change and the concepts and actions of motivational interviewing to become mentors. Teaching also delivered to the CHN's on telephone coaching, the IT system being used and motivational interviewing. The mentors then supported patients with COPD who kept a diary and acted upon deterioration of symptoms as taught to do so by the mentors.	21 CHN's across 4 centres.	26 feedback meetings from 21 CHN's.	Thematic analysis of transcriptions from feedback meetings.	Research team conducted the education of the CHN's, the feedback meetings and the data analysis which may affect the reliability of results.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
3. Reinke et al. (2011)	USA	Age (mean) $\pm SD$) 68$\pm$ 4 FEV¹ % predicted 33 $\pm$ 15	Assessment of the effects of a webinar entitled 'Difficult conversations' for patients with very severe COPD60-minute pre-webinar training session 3 open group sessions prior to each webinar to allow participants to become familiar with each other Participants then took part in 60 minute webinar to equip patients with knowledge and skills to make decisions upon end of life care	7 participants	Survey 1-2 days' pre-webinar Survey post-webinar	Descriptive statistics and presentation of direct quotations. No inferential statistics performed.	Very small sample size – will impact upon generalisability

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
4. Wang et al. (2012)	Norway	Patients with a diagnosis of COPD. GOLD stage 3 – 6 patients All participants had mMRC >2	Specialised hospital at home nurse visited patients for one hour per day for 3 days' post hospital discharge. Control group remained in hospital. Intervention group received an evaluation of clinical status and education on future exacerbations with spouse.	9 participants 6 Intervention 3 Usual care	Semi-structured in depth interviews	Systematic text condensing	Lead researcher undertook data collection and analysis alongside intervention development. Verification of interview transcripts by participants absent.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
5. Apps et al. (2013)	United Kingdom	Patients with a diagnosis of COPD. All participants with mMRC >2	Co-creation of SPACE for COPD intervention for further test within RCT	24 participants comprising of patients with COPD, their carers /relatives and healthcare professionals	Focus Groups	Thematic analysis	Lead researcher led the focus group and analysed the data. Very balanced discussion given, impact very minimal.
6. Benzo et al. (2013)	USA	Patients with a diagnosis of severe COPD	Eight weekly sessions where participants learn key behaviours for COPD management. Seven further sessions on self-management action planning	11 participants	Semi-structured interviews via telephone	Content analysis	Small participant sample.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
7. Benzo (2013)	USA	Diagnosis of severe COPD FEV¹ % predicted – mean 29% ± 8 mMRC >2 – all participants	Motivational Interviewing – 10 telephone calls over three weeks by a nurse trained in motivational interviewing Participants kept a daily log of physical activity and symptoms. Mindfulness – eight weekly two hour sessions and one monthly meeting. CD given to practice mindfulness.	Motivational Interviewing – 51 participants Mindfulness – 10 participants	Semi-structured, open-ended questions by telephone interview	Content analysis leading to grounded theory	Small sample size within mindfulness group.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
8. Kennedy et al. (2013)	United Kingdom	Healthcare professionals – experience of managing patients with COPD between 2-22 years	Study conducted 3-6 months' post-delivery of self-management intervention. Focus upon the implementation of 2 tools: Self-management guidebook Shared decision making tool to form collaborative partnerships with patients.	11 practice Nurses 1 assistant practitioner	Face to face semi-structured interviews	Normalisation Process Theory Framework	All nurse female All authors contributed to the data coding and had been involved within the implementation of the intervention.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
9. Meis et al. (2013)	Netherlands	GOLD stage 3 – 7 patients GOLD stage 4- 2 patients Mean FEV¹ (% Predicted) – 45.6%	Pulmonary rehabilitation programme with the study focus being upon social cognitive theory, self-determination theory, exercise self-efficacy, motivation, goal setting and outcome expectations	13 Patients 14 Healthcare professionals	Patients – two focus groups and interview HCP's – Focus group and interview	Phenomenological approach	Lead researcher completed data collection and analysis potentially impacting upon the interpretation of results

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
10. Simpson and Jones (2013)	Scotland	17 participants – FEV^1 % predicted 20-49% 25 participants – mMRC >2	Qualitative study to determine if self-efficacy within COPD is related to improved mood, reduced breathlessness and reduced COPD exacerbations. To determine what helps or hinders in COPD management and the suggestions patients have to improve programmes of COPD self-management.	48 participants	Descriptive surveys with semi-structured and open questions	Content analysis	Poor description of study methods given hindering reproducibility. Themes within results not explicitly demonstrated

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
11. Davies et al. (2014)	Netherlands, Russia, Norway, Wales, Germany, Poland and China	General practitioners and Pulmonologists	A qualitative study to explore the views of general practitioners and Pulmonologists upon self-treatment within COPD	142 clinicians	Focus groups	Thematic analysis	No limitations identified. No conflicts of interest
12. Sohanpal (2014)	England	mMRC>2	A qualitative study to understand the patient perspectives upon non-completion of self-management interventions	22 patient participants	Semi-structured interviews	Thematic framework approach	Sample - 4 males and 18 female making generalisations of results across both genders difficult.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
13. Williams et al. (2014)	England	Age (mean) 67 years (50-85) 10 – GOLD 3 3 – GOLD 4 mMRC >2	The evaluation of the EDGE COPD project – a touch screen health monitoring intervention allowing remote self-monitoring (oximetry), multimedia education materials (videos, text and images).	19 participants provided pre-intervention interviews. 15 participants gave post-intervention interviews.	Longitudinal individual in-depth interviews	Grounded theory approach through a constant coding model utilising coding and memo-writing	Small study sample

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
14. Buckingham et al. (2014)	Scotland	All patient participants had mMRC >2 Healthcare professionals with experience of working with patients with COPD.		8 patients provided 12 interviews. 28 social or health professionals provided interviews	Interviews via telephone	Thematic analysis	Small patient study sample
15. Burkow et al. (2015)	Norway	GOLD stage 3 – 4 participants Mean FEV¹ (% predicted) – 40.3	Nine-week internet enabled home pulmonary rehabilitation. Content included disease education and exercise programme with a step counter to encourage walking.	10 patient participants	Semi-structured interviews using open and closed questions	Thematic analysis through descriptive interpretation	Small study sample

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
16. MacNab (2015)	Scotland	Age (mean) $\pm SD$) 69.7 ± 8.4 Symptomatic of COPD – mMRC >3	Feasibility study of light touch telephone service helpline based on COPD symptoms and oximetry. Participants able to contact a respiratory-trained community team via a telephone helpline over a 6-month period.	51 participants. 28 participants provided 36 interviews. 8 clinicians contributed to focus groups. 6 managers provided interviews.	Paired, face to face semi-structured interviews	Thematic analysis using a framework approach.	Small study numbers

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
17. Mathar (2015)	Denmark	GOLD stage 3 – 4 participants GOLD stage 4 – 2 participants	Eight thirty minute televideo consultations over two weeks by community nurses and physiotherapists. Consultations included the taking of observations, medication support and the installation of an emergency alarm.	6 patients – 3 Male/ 3 Female	Interviews Using open, explorative questions	Systematic text-condensation method	Small study sample. Lead researcher present at interviews.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
18. Young et al. (2015)	United Kingdom	Healthcare professionals mean years of respiratory experience – 7.53	A qualitative study to explore nurses and allied health professionals understanding of self-management and the challenges in delivery.	14 healthcare professionals – all female	Face to face semi-structured interviews by a researcher unknown to the participants	Thematic analysis	Sample all female. No exploration of formal self-management training in other chronic disease management that may have affected the study results.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
19. Chen (2016)	Taiwan	GOLD stage 3 – 8 participants GOLD stage 4 – 1 participant	A qualitative inquiry to explore self-management form the perspectives of patients with COPD	19 participants – all Male	Face to face, semi-structured interviews	Thematic analysis independently undertaken. Two participants validated interpretations	Sample all Male – affects generalisability . Purposive sampling used so selected participants meet the criteria.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
20. Harrison et al. (2016)	United Kingdom	Patients Mean FEV^1 (% predicted) 8 had experience of mindfulness/yoga/ meditation Healthcare professionals – all had >2 years' experience within COPD care 13 had experience of mindfulness/yoga/ meditation	Qualitative study to determine perceptions of patients and healthcare professionals upon the use of mindfulness in COPD	20 healthcare professionals 19 patients	Semi-structured interviews	Deductive thematic synthesis	No interviewee transcript review

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
21. Blackmore et al. (2017)	United Kingdom	Healthcare professional criteria. All had in excess of two years' experience of managing COPD patients	The identification of training needs for healthcare professionals to deliver a self-management intervention for patients with COPD. Subsequent development of a training program to address these needs.	14 healthcare professionals All female	Semi-structured interviews	Thematic analysis	Small study sample – may limit generalizability All participants were female.
22. Bove et al. (2017)	Denmark	Mean FEV^1 (% predicted) 32 Mean mMRC – 4.1	Single, home-based one-hour intervention based upon CBT and psychoeducation. Followed by 20-minute telephone booster session two weeks later accompanied by the use of a manual.	20 patients	Semi-structured interviews	Interpretive description	Six of the 20 interviews were completed with a spouse present.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
23. Early (2017)	England	Group 1 meet inclusion criteria Mean FEV¹ (% predicted) – 25.4 GOLD Stage 3 & 4 – Classification D mMRC – 4/5	Off-the-shelf Internet based health-promotion program (The Preventative Plan –TPP) coupled with nurse-coach support. The tool comprised of the uploading of personalised information and the creation of a personalised plan. A message facility to contact a trained respiratory nurse was also present. The nurse provided home visits, telephone and email support.	11 participants within Group 1	Semi-structured interviews	Thematic analysis through deductive coding framework	Only eight participants completed the three-month follow up limiting the understanding of long-term intervention impact.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
24. Nissen and Lindhart (2017)	Denmark	Mean mMRC – 4 FEV^1 (% predicted) - 32	Telemedicine intervention over six-months. Each participant given a tablet computer with a web camera, microphone and measurement equipment. Participants had to submit physiological measurements thrice weekly for the first month and weekly thereafter. Responses were coded (green, yellow, red) and participants contacted by a respiratory nurse for all yellow and red calls.	14 participants	Semi-structured interviews via video-link	Manifest and latent content analysis	Small sample size affecting generalisability of results.

Source Paper (n=25)	Country Setting	Participant Demographic Data	Self-management Intervention	Participant sample	Data Collection Method	Data Analysis Method	Study Limitations
25. Russell et al. (2017)	England	Systematic Review Used for Healthcare professional views only.		31 eligible studies	Literature search of 5 databases	Meta-ethnography	Minimal database search limiting results for consideration to be included/excluded in systematic review

4.10 – Risk of Bias in individual studies

The overall risk of bias for each study will be reflected throughout the meta-ethnographical analysis of the studies as a whole, with those studies containing a high risk of bias holding limited weight within this systematic review's findings to maintain the validity and reliability of the study.

4.11 – Data Synthesis

The 25 qualitative studies were synthesized using the seven steps of meta-ethnography (Noblit and Hare 1988), allowing for logical comparisons by translating the studies into each other to develop new concepts to determine the use of self-management as a coping strategy for people with COPD at the end of life.

Each included paper was read and re-read to allow for an in-depth understanding of the papers alongside the initial identification of similar and differing metaphors and concepts used within each study and across all studies as a whole. The raw data findings of each study were separated into individual text units and coded by words, sentences or paragraphs dependent upon content to formulate concepts to describe the characteristics identified within each study. Meta-ethnography allows for study comparison in a number of ways depicted by the relationship between included studies (Noblit and Hare 1988). At this point within data synthesis, consideration was given to a variety of comparative methods to determine the most appropriate for this study. A refutational synthesis approach allows for the comparison of studies when the identified concepts contest each other by the presence of differing perspectives (Campbell et al. 2003, Pope and Mays 2007) and therefore would be inappropriate for this study as the 25 included papers have been found to present similar perspectives upon the use of self-management at the end of life. Another approach considered was a line of argument synthesis to allow for the interpretations from each study to reveal a whole perspective to answer the research question (Pope and Mays 2007, Thomas, Harden and Newman 2012). This approach does not align with the aims and objectives of this study as its purpose is not to identify a single underlying truth but to determine a number of concepts to explore the differing elements of coping with COPD at the end of life, from a number of human perspectives.

The chosen method of synthesis for this study was therefore a reciprocal translation allowing for the identified metaphors from each included study to by synthesised into overarching

concepts to answer each of the studies' aims (Campbell et al. 2003). The reciprocal translation process allows for the direct comparison of commonly identified concepts alongside the explicit identification of any differing meanings. As the included studies are of similar content, this method is appropriate (Noblit and Hare 1988). The synthesis of the included studies was initially undertaken by the lead researcher then subsequent support and clarification obtained from the supervisory team.

The reciprocal translation of the studies is displayed within Table 13 and the identified seven concepts further explored within Chapter 5.0. The translation has been divided into two sections, firstly the perceptions of patients and carers and secondly, the perceptions of healthcare professionals to allow for the concepts to explicitly reflect the initial study content and preserve each perspectives true meaning.

4.12 - Confidence in Cumulative Estimate

The need for confidence within the findings of a systematic review is paramount to provide high quality evidence and enable its acceptance across the knowledge base within the chosen field of study.

Within the protocol development for this study, the use of the Grading of Recommendations Assessment, Development and Evaluation tool (GRADE) was specified as the chosen method to assess the confidence in cumulative estimate. A pilot application of the GRADE tool identified it would not meet the needs of this systematic review due to its quantitative focus making elements of the appraisal criteria inappropriate to use with qualitative studies. Therefore, a tool specifically designed to be used when assessing study quality of qualitative studies was adopted, the ConQual approach.

The ConQual approach assesses the quality of cumulative study synthesis by focussing upon combined study dependability and credibility (Munn et al. 2014). A ranking system is used to determine the dependability of a systematic review of multiple studies based upon the response to five critical appraisal questions as demonstrated within Figure 10. The critical appraisal findings are applied to the overall systematic review findings and not that of the individual included studies as this has been considered within the data extraction and risk of bias processes as described earlier within this chapter.

Figure 10.0 – ConQual Dependability Assessment (Munn et al. 2014)

The overall study findings are then appraised against three credibility criteria as demonstrated within Figure 11 and a ranking given to each identified concept.

Some materials have been removed from this thesis due to Third Party Copyright. The unabridged version of the thesis can be viewed at the Lanchester Library, Coventry University.

Figure 11.0 – ConQual Credibility Assessment (Munn et al. 2014)

An overall confidence score of either High, Moderate, Low and Very Low is then given to each finding. The ConQual confidence in cumulative estimate results for this study are demonstrated within Table 14 and will hold weight within any conclusions made.

Table 12.0 -– ConQual Confidence in Cumulative Estimate

Synthesised Finding	Type of Research	Dependability	Explanation	Credibility	Explanation	ConQual score
Acceptance and Adjustment	Qualitative	Downgrade 1 level	Common dependability issues across studies due to potential researcher influences upon their research	No change	Studies present unequivocal findings upon this concept	Moderate confidence
Dependence	Qualitative	No Change	Studies present unequivocal findings upon this concept	No change	Studies present unequivocal findings upon this concept	High confidence
Self-management	Qualitative	No Change	Studies present unequivocal findings upon this concept	No change	Studies present unequivocal findings upon this concept	High confidence

Synthesised Finding	Type of Research	Dependability	Explanation	Credibility	Explanation	ConQual score
Enabling Coping	Qualitative	No change	Studies present unequivocal findings upon this concept	No change	Studies present unequivocal findings upon this concept	High confidence
Wisdom	Qualitative	Downgrade 1 level	Common dependability issues across studies due to potential researcher influences upon their research	Downgrade 1 level	Some included studies do lack clear association between findings and concept	Moderate confidence
Preconceptions and insight	Qualitative	Downgrade 1 level	Common dependability issues across studies due to potential researcher influences upon their research	No change	Studies present unequivocal findings upon this concept	Moderate confidence

Synthesised Finding	Type of Research	Dependability	Explanation	Credibility	Explanation	ConQual score
Barriers to implementation	Qualitative	No change	Studies present unequivocal findings upon this concept	No change	Studies present unequivocal findings upon this concept	High confidence

Chapter - 5.0 – Findings

From the reciprocal translation of the 25 included studies, the development of seven new concepts has enabled an exploration of the perceptions of patients and healthcare professionals upon the use of self-management as a coping strategy for people living with COPD at the end of life. Five of these concepts arise from the perceptions of patients and carers and are displayed within Figure 12. Two concepts were developed from the perceptions of healthcare professionals and are demonstrated within Figure 13. The findings within each concept will be further explored throughout this chapter.

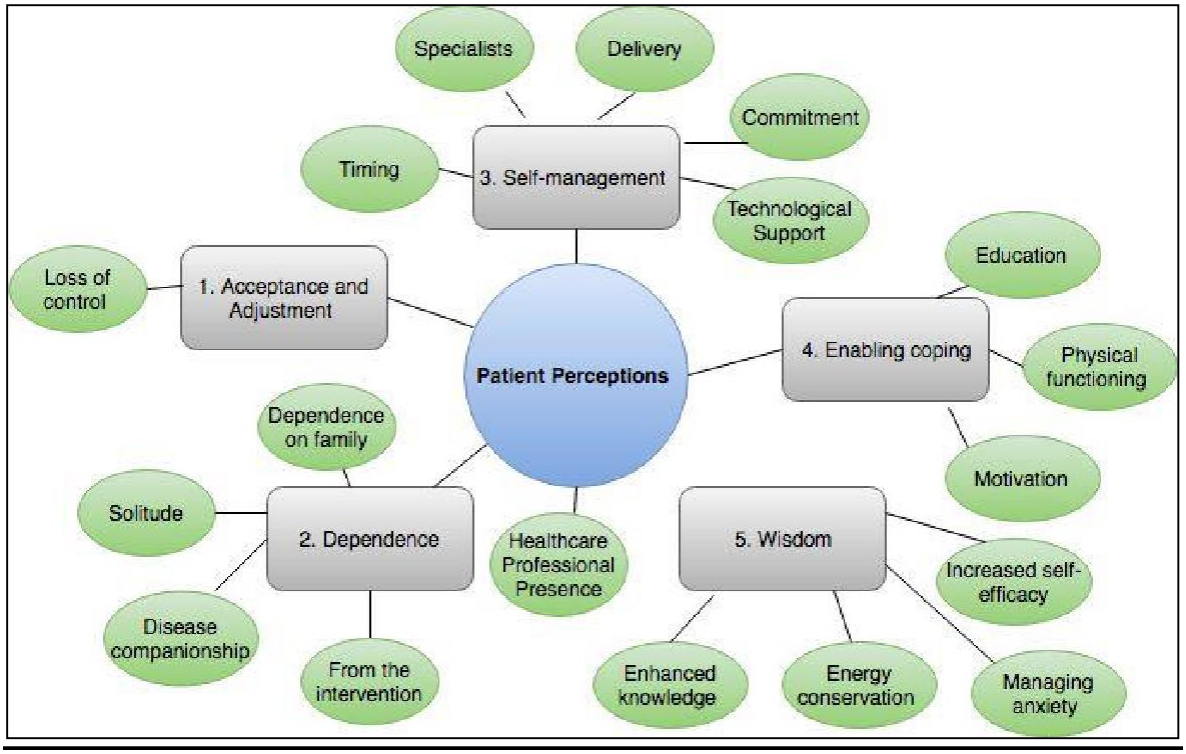

Figure 12.0 – Conceptual diagram of patient perceptions

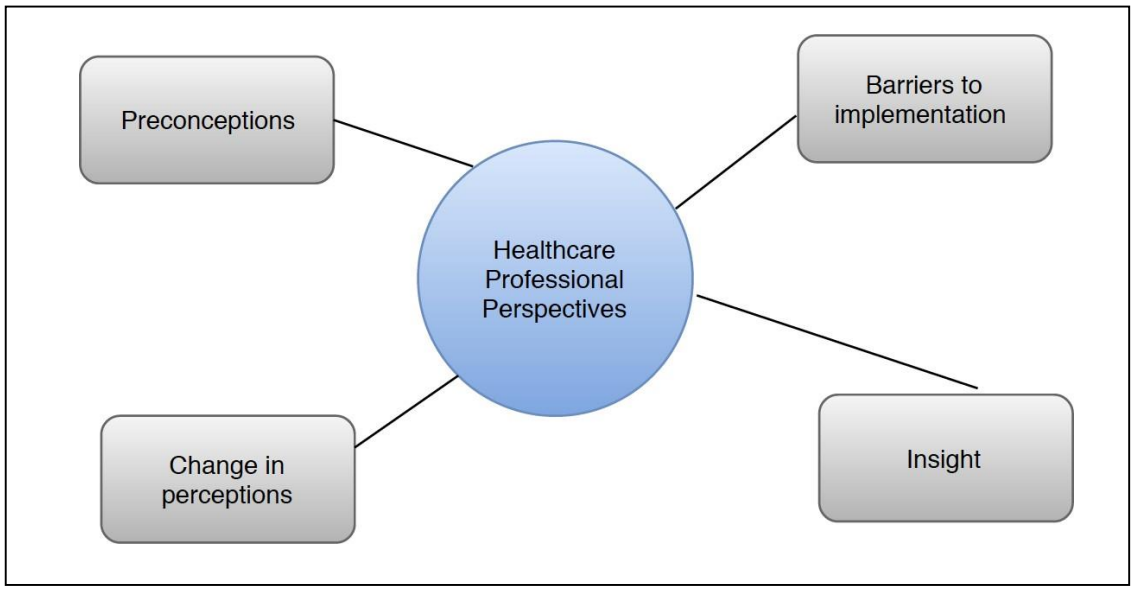

Figure 13.0 - Conceptual diagram of healthcare professional perceptions

Patient Perceptions

5.1 – Acceptance and Adjustment

Adjustments in lifestyle and coping as a result of having COPD and the process of acceptance of living with COPD at the end of life emerged from the data within the majority of included studies. Difficulty with disease acceptance and adjustment created a barrier to the participation and implementation of interventions to enhance self-management abilities. The reciprocal translation of included studies into the concept of acceptance and adjustment are displayed within Table 13.

Firstly, in terms of adjustment, patient perceptions of a loss of control upon their life and subsequent physical abilities is found to hinder adjustment to living with the disease, and consequently their perceived self-efficacy in the ability to participate within self-management interventions (Bove et al. 2017, Chen et al. 2016, Mathar, Fastholm and Sandholm 2015, Sohanpal 2015). Secondly, understanding the incurable nature of COPD and the subsequent feeling of this being beyond their control can result in failure to fully appreciate the benefit of such self-management interventions. In part this might be due to the fact such interventions arguably offer no real cure for the disease (Sohanpal 2015).

Table 13.0 - Reciprocal Translations of included studies within the concept of Acceptance and Adjustment

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Acceptance and Adjustment	Now I have accepted that I have a chronic disease…..um we must regulate self-care models ourselves' [19]	Disease management process of self-regulation [19]
	'doesn't see COPD as his problem' [2]	Acceptance of reduced energy [1]
	'I just can't accept that I can no longer do many everyday things' [9]	Barriers to promoting self-efficacy [2]
	'the more you know the more frightened you get, because it's almost like acceptance that there is something wrong with them' [12]	Difficulty with acceptance [9]
	'the more you know, the more frightened you get' [12]	Resignation [12]
		Barriers to participation in SM [12]
- Loss of control	'How can I recover from this?' [19] 'Perhaps they think, well, you're never going to be cured, because your lungs are not any much good with that' [12]	Disease related cognitions [19]

Consequently, acceptance of living with COPD at the end of life was found to be an understandably difficult process for patients with the required adjustment to undertaking daily tasks being an overwhelming concept for individuals (Chen et al. 2016, Meis et al. 2013, Monninkhof et al. 2004, Robinson et al. 2008a, Sohanpal 2015) . As displayed within Table 13, as presented by Meis et al. (2013), one patient voiced *'I just cannot accept that I can no longer do many everyday things'*. Within this study and two further included studies (Chen et al. 2016, Monninkhof et al. 2004), the interpretations presented suggest the process of disease acceptance to be adopted throughout participation within self-management interventions, consequential of the acquired disease related knowledge. Conversely, Russell et al (2017) suggests confusion of COPD related knowledge due to the differences within information given from healthcare professionals hinders disease acceptance. Contrastingly, another study (Sohanpal 2015) presented findings of an increase in disease knowledge leading to feelings of fear and vulnerability when beginning to accept living with COPD, as the knowledge gained of the disease trajectory, inevitable debilitation and reduced social opportunities allowed patients to see little benefit within health improvement behaviours. Concealment of symptoms and denial of the actual impact of such severe COPD were also found to demonstrate disease non-acceptance (Chen et al. 2016, Meis et al. 2013, Robinson et al. 2008a). Disease acceptance is believed to be required in order to facilitate patients enhancing their self-management abilities and allowing the setting of achievable self-management goals (Chen et al. 2016, Sohanpal 2015). Within some studies, patients continued to deny the impact of their disease even whilst taking part within an intervention and feel they are aware of how to best manage their disease, for example, as found by Chen (2016) '*No matter what healthcare professionals say, the most important thing is doing things by myself'* (See Table 13).

5.2 - Dependence

The concept of dependence upon others for those living with COPD at the end of life emerged throughout the synthesis of studies as a strong theme both within and outside of programmes of self-management enhancement as displayed within Table 14.

Table 14.0 - Reciprocal translations of included studies within the concept of dependence – Sub-themes: Solitude and Disease companionship

Concept / - Categories	**Quotations from participants in primary studies** **[Study reference number as detailed within Table 9.0]**	**Interpretations of findings offered by authors**
Dependence - Solitude	'Many people living with COPD are lonely, and so on……. It's pretty depressing' [17]	Loss of control [17]
	'the hospital is a bit of a refuge where one can get away from the everyday things one needs to sort out…. so you can say, it shows how boring my life is when you are glad to be in hospital' [17]	
	'The control or feeling that somebody cared about you. I experienced that for the first time on the screen' [17]	
	'it just occupies so much space' [24]	

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
- Disease Companionship	'It is important that you meet people again' [1]	Increased social function due to group exercise sessions [1]
	'and then you think to yourself: I'm not the only one who has COPD' [1]	Perception that the programme is a social activity [1]
	'because it indicates that someone actually cares and is listening to them' [2]	Benefit from peer group support. [1]
	'we are all in the same boat, we all know why we are here, that's stimulating [9]	Learning from others [7]
	'very good to meet others with the same illness' [15]	Supportive social environment [15]
	'even though you were kind of far away, they were so close to you' [15]	Sharing of experiences [7]
	'we learned from each other too' [15]	Group education [15]
	'you can exchange experiences and share advice' [15]	

Overwhelming feelings of solitude were identified amongst participants with COPD at the end of life (Bove et al. 2017, Mathar, Fastholm and Sandholm 2015, Nissen and Lindhart 2017), leading them to feel lonely, isolated and low in mood, creating a dependence upon others and programmes of care. Included studies identified the comfort and company patients received from hospitalisation or participation within self-management interventions alongside the subsequent removal of feelings of solitude. Within one study (Mathar, Fastholm and Sandholm 2015), a patient expressed their first feelings of being cared for as a result of participation within a technology assisted self-management intervention as displayed with Table 15 as '*The control or feeling somebody cared about you. I experienced that for the first time on the screen'* (from Mathar, Fastholm and Sandholm 2015).

Table 15.0 - Reciprocal translations of included studies within the concept of dependence – Sub-theme: Dependence upon healthcare professionals

Concept / - Categories	**Quotations from participants in primary studies** **[Study reference number as detailed within Table 9.0]**	**Interpretations of findings offered by authors**
Presence of Healthcare Professionals	'Thank you for being interested' [2]	Benefits of contact between patients and healthcare professionals [2]
	'because it indicates that someone actually cares and is listening to them' [2]	Feeling safe was the patients main experience [4]
	'very reassuring' [4]	Nurse had allocated time for each individual [4]

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Presence of Healthcare Professionals	'it was safe, because I knew she was coming!' [4]	Believing them [10]
	'one feels safe when doctors and nurses are present. I believe it's quite natural' [4]	Trust [11]
	'being there when they needed advice' [10]	Supervision [15]
	'Many will prefer talking to their doctors' [11]	Relatedness [9]
	'the most helpful thing is talking to the nurse about different things' [23]	

From the synthesis of studies, patient dependence originated from three sources, dependence upon healthcare professionals, dependence upon the self-management intervention and dependence upon family. The dependence of patients with COPD at the end of life upon healthcare professionals is underpinned by the feelings of safety brought by healthcare professional contact as shown within Table 15. Feelings of trust and the belief of help were developed through participants attending self-management interventions (Davies et al. 2014, Simpson and Jones 2013, Wang et al. 2012) and as a result gave reassurance when the patients perceived help was required (Davies et al. 2014, Early et al. 2017, Wang et al. 2012). This finding does detract from the purpose of self-management interventions to

enhance patient's abilities to change their own health behaviours, and leads to findings that patients perceive the interventions as a way of gaining further healthcare professional support.

Patients reported perceived positive aspects of self-management (as displayed within Table 16), interventions that included dependence upon the understanding that someone (a healthcare professional) was 'checking everything's all right' (Apps et al. 2013a). This was also demonstrated when exploring the impact of technology based interventions with participants believing access to monitoring equipment, such as pulse oximetry measurements, gave them confidence to take control of their illness alongside assisting in the minimisation of worry (MacNab et al. 2015, Nissen and Lindhart 2017). Contrastingly, one study (Mathar, Fastholm and Sandholm 2015) concluded that none of the six participants with severe and very severe COPD wished to participate within tele-video consultations again despite them voicing the increased feelings of security it brought, suggesting not all patients require this level of dependence. Dependence upon self-management aids such as a manual were perceived by patients positively, allowing the feeling that assistance with self-managing their condition was present through being able to refer to the manual to refresh knowledge (Apps et al. 2013a). Interestingly, the interventions delivered with self-management aids including technology based aids, were perceived as a continuation of care, possibly influenced by the belief of healthcare professional support behind them giving reassurance to participate (Nissen and Lindhart 2017, Williams et al. 2001).

Patients with a chronic debilitating disease such as COPD will require some degree of direct care delivery and support in order to maintain health and function and the complete removal of healthcare professional input is not the purpose of enhancing self-management abilities. The reporting of patients with COPD at the end of life utilising self-management resources such as manuals and technology based assistance (Apps et al. 2013a, MacNab et al. 2015) demonstrates the possibility for dependence to be delegated from one source of reassurance

and re-clarification of knowledge to another however within one study (Early et al. 2017), the collaboration of both healthcare professional delivery and a supplementary aid was deemed to be most acceptable to patients.

Table 16.0 - Reciprocal translations of included studies within the concept of dependence – Sub-theme: Dependence upon the intervention

Concept / - Categories	**Quotations from participants in primary studies** **[Study reference number as detailed within Table 9.0]**	**Interpretations of findings offered by authors**
- From the Intervention	'The more you know, the safer you feel' [4]	Increased awareness of symptoms [13]
	'(the manual) it's there for you' [5]	Reassurance of being looked after [13]
	' that there's someone else thinking about you and just checking everything's all right' [5]	Guide to wellbeing [16]
	'so I listen to you and I don't want to hear…..Don't want to listen to it, I don't want to be scared……' [12]	
	'if you're feeling a bit down, you got to say what you feel' [13]	
	'It (the oximeter) saves me worrying, getting up tight about my breathing and that' [16]	

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
- From the intervention	'well if it's taken off me, I'll buy one for myself as it gave me more confidence to take control' [16]	
	'It means that I am not anxious…..because I can control how I am….I can get in contact with you very quickly' [24]	

The dependence upon the social interaction received from self-management interventions was echoed through patients views of experienced disease companionship as shown within Table 14. Sharing the company of others with advanced COPD and the subsequent informal support this facilitates was evident through many studies (Benzo 2013, Burkow et al. 2013, Meis et al. 2013, Monninkhof et al. 2004, Robinson et al. 2008b). Patients reported learning from each other through the exchange of experiences to be of benefit to them with attendance at group sessions or group interaction via technology created supportive social environments combating the feelings of solitude (Burkow et al. 2013, Monninkhof et al. 2004, Robinson et al. 2008b).

From the synthesis of studies, there is no evidence that the resulting disease companionship of self-management interventions explicitly enhanced patients' abilities to self-manage, with one study reporting findings of the intervention being perceived as a social activity as opposed to a programme of health improvement (Monninkhof et al. 2004), developing

dependence of peer support when engaging with and attending programmes aimed to enhance self-management behaviours.

Table 17.0 - Reciprocal translations of included studies within the concept of dependence – Sub-theme: Dependence upon family members

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
- Dependence on family	my wife will always support me' [9]	Choosing suitable healthcare behaviours [19]
	'the best nurse I have is my wife and she will definitely tell me when I am ill' [17]	Many types of assistance [19]
	'all of my children were responsible' [19]	
	'my wife stays on me to walk every day.' [19]	
	'and my wife never left me alone' [19]	
	'my wife now understands my condition better, but she doesn't know how to cope with it' [9]	
	'your entire family has to cope with the consequences of the disease, especially when they don't understand' [9]	

Dependence upon family members was a further strong theme identified throughout the translation of studies and the level of trust patients with COPD at the end of life have in their abilities to assist them is evident (Chen et al. 2016, Mathar, Fastholm and Sandholm 2015), as demonstrated within Table 17.Patients voiced their opinions of how family members deliver support, feelings of safety and assist them in understanding when their condition changes (Chen et al. 2016, Mathar, Fastholm and Sandholm 2015, Meis et al. 2013). The value of family input within facilitating the management of their condition is evidently valuable as shown within Table 17 as *'the best nurse I have is my wife and she will definitely tell me when I am ill'* (from Mathar, Fastholm and Sandholm 2015).

Within the included studies, the perceptions of carers upon the use of self-management interventions within COPD at the end of life was little explored, despite one study having family present at data collection interviews, their opinions were not captured (Bove et al. 2017). Findings from the study demonstrated little facilitation in assisting with encouragement of self-management behaviours by family members apart from within one study (Chen et al. 2016), with a patient voicing how his wife encourages him to exercise each day. The lack of family understanding of COPD and the progression of the disease was evident, with the impact of the disease perceived to impact upon the whole family (Chen et al. 2016, Meis et al. 2013).

5.3 – Self-management

Patient perceptions of self-management interventions were expressed throughout each of the included studies and constructed four sub-themes of *timing of intervention delivery*, intervention delivery by specialists, method of intervention and the use of technological support.

The timing of the implementation of a self-management intervention was found to be key in its acceptance (Apps et al. 2013a, Benzo et al. 2013, Sohanpal 2015). For patients with COPD at the end of life, some would have preferred to have participated within an intervention at the time of diagnosis or soon after to allow for the acquisition of disease knowledge and coping strategies to use throughout disease progression (Apps et al. 2013a, Sohanpal 2015), whilst other participants within the same study felt that instigating a programme of self-management with a patient newly diagnosed with COPD would not be of benefit as demonstrated within Table 18. It is clear across all included studies that there is no known optimal time of implementation leading to successful adoption of self-management behaviours impacting at the end of life, and that each individual will both require and prefer this information at differing times throughout disease progression dependent upon the stage of disease progression and their acceptance of and adjustment to living with COPD.

Table 18.0 - Reciprocal translations of included studies within the concept of dependence – Sub-themes: Timing and Specialists

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
- Timing	‘ if they’d given me the information 10-15 years ago, I would’ve sat down and read it and I’d known what I’d got to do’ [5]	Intervention delivery early in disease progression [5]
	‘ recently diagnosed with this problem, it would help’ [5]	Timing is key to acceptance [12]
	‘yeah, because when you first get it (the condition) and you go to these (programmes), it would help you manage it a bit better….’ [12]	Healthcare professional to be knowledgeable of COPD [5]
- Specialists	‘I think professionals who know the people’ [5]	Participation by avoiding prescriptive behaviour [6]
	‘I haven’t got a lot of faith in GP’s’ [5]	Participants emphasise the desire for follow up [5]

Patients preferred that COPD specialists, rather than non-specialists, delivered the self-management intervention with some studies identifying patients having little faith in the knowledge of non-specialist disease support (Apps et al. 2013b, Benzo et al. 2013, Harrison et al. 2016). Patients having faith in the knowledge and skills of their assigned healthcare

professional is paramount to facilitating patient engagement. The findings from two studies (shown within Table 19), presented that the use of specialist input encouraged participation within self-management interventions by creating a less prescriptive approach to intervention delivery and more of a facilitation the development of self-management skills (Benzo et al. 2013, Harrison et al. 2016) , a key concept of delivering programmes to enhance health-behaviour change. Contrastingly, within an included systematic review (Russell et al. 2018), patients had reported frustration with conflicting advice from healthcare professionals upon self-managing COPD, concluding the requirement of a multi-disciplinary approach would be more beneficial to the patient.

Table 19.0 - Reciprocal translations of included studies within the concept of dependence – Sub-themes: Delivery and Commitment

Concept / - Categories	**Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]**	**Interpretations of findings offered by authors**
-Delivery	'face to face for starters' [5]	Faith in healthcare professional's delivery [6]
	'perhaps phone calls to people would help to try and motivate people' [5]	Patient-Practitioner relationships [25]
	'I've always felt that face to face s best' [5]	Controlled and balanced motivation [9]
		Effect of treatment beliefs [12]
		Buy in can be a challenge [20]

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
- Commitment	'it doesn't matter what age you are, as you've just said, you're going to do something about this' [5]	
	'I find it hard that my freedom is restricted' [9]	
	'in my opinion, were getting enough freedom' [9]	
	'no because it costs money…. I'd have to get a minicab there and 'I'd have to have a minicab back, and I just can't afford it' [12]	
	'I don't want to sit and listen to mind music and just I find it a waste of time' [20]	
	'if I have one of those screens, I will be stuck at home now' [17]	
	'I think it was really irritating…. I sat there waiting in front of that screen' [17]	

The synthesis of findings demonstrated that the preference mode of delivery of a self-management intervention was found be face to face, with study authors believing this impacted upon the patient's trust in healthcare professionals (Benzo et al. 2013, Meis et al. 2013, Russell et al. 2018, Sohanpal 2015). The face to face approach to the delivery of an intervention was found to have a positive effect upon patient motivation (Meis et al. 2013) alongside the use of telephone call follow up to assist with motivation (Benzo et al. 2013). Upon synthesis of the included studies, the theme that patients prefer healthcare professional contact as opposed to a manual or technological application was evident with an underlying truth emerging that the support received was of more benefit that the intervention itself for patients with COPD at the end of life. The desire to want to form a relationship with their healthcare professional was clear from the raw data extracted from studies, however no study reported this within their findings.

Patients voiced conflicting views upon group delivery of interventions. Some studies found they were very much accepted and supported the concept of disease companionship reported within section 5.2, however some patients felt that a group setting may cause some to feel uncomfortable and may impact upon participation within the sessions.

The use of technological support, such as webinars for online education and interactive physiological observation measurements, as a method of delivering self-management interventions is perceived to have both facilitators and barriers to its acceptance as demonstrated within Table 20. The technology based interventions gave patients feelings of encouragement and reassurance that a healthcare professional is behind the technology monitoring their behaviours, enhancing the feeling of safety (Mathar, Fastholm and Sandholm 2015, Williams et al. 2014). This perception is different from the intended use within the study design of facilitating patients to become more independent when managing their condition and a strong theme of the underlying healthcare professional support was identified as being of more benefit than the actual intervention content itself – *'it's nice to*

know you've got it…. your being monitored you know….so you get that feeling you are being looked after' (Williams et al. 2014).

Table 20.0 - Reciprocal translations of included studies within the concept of dependence – Sub-theme: Technological Support

Concept / - Categories	**Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]**	**Interpretations of findings offered by authors**
Technological Support	'I'm quite pleased with myself' [13]	Perceived continuity of care [13]
- Facilitators	'it's nice to know you've got it…. your being monitored you know….so you get that feeling you are being looked after' [13]	General approval [15]
	'you being looked after really… I did like the idea that someone will be looking over me' [13]	Virtual consultation a virtue [24]
	'it encourages me to do what I call breathing exercises' [13]	
	'fantastic for those who live so far away from the hospital' [15]	
	'it was not intrusive in any way' [15]	
	'I think it's reassuring and calmer' [17]	

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Technological Support	'I'm not sure this technology is suitable for this type of discussion (end of life) [3]	
- Barriers	'difficult to discuss something like this when you couldn't see people's faces' [3]	
	'you couldn't tell who was speaking (online group discussion) [3]	
	'I was unable to read the information on the screen' [3]	
	'no I wouldn't cope with something like that (technology). I'm too old to bother' [13]	
	'it's a job when your old' [13]	
	'I can't be bothered with new stuff' [13]	
	'it was a waste of time, they (respiratory nurses) tell me to do this when I am not well' [13]	
	'I feel I am doing it because it is helping them do research, but…. I don't see it doing me any good' [16]	

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Technological Support	'At least it's (pulse oximetry) written down for them. It helps them to understand it, at least I think it does' [16]	
- Barriers	'it's (the e-health healthcare professional contact) at a fixed time…if I have a panic attack and feel poorly, all I can do is call the emergency services' [17]	

Barriers upon the use of technological support appeared to be a much stronger theme than facilitators as demonstrated within Table 20. Practical barriers of the use of the technology prevented engagement with the intervention such as being unable to read the screen and being unable to determine who was speaking within group sessions (Reinke et al. 2011). Furthermore, patients believed they would not cope with using technology due to their age (Williams et al. 2014) – '*I'm too old'*. Within two studies (MacNab et al. 2015, Mathar, Fastholm and Sandholm 2015), patients voiced their perception of the reason for the technological intervention being to assist healthcare professionals with research with no acknowledgment given to the benefit to them managing with their disease. Interestingly, all participants within one study (Reinke et al. 2011) did not wish to participate within technology assisted education again.

An included study using a webinar approach to explicitly discuss end of life care with patients (Reinke et al. 2011) was deemed as an inappropriate way of addressing such sensitive education needs with participants due to the absence of physically being able to see whom they were taking to.

5.4 Enabling Coping

Perceptions by patients of self-management interventions enabling coping behaviours was identified through the synthesis of included studies and produced four sub-themes: Education, Physical Functioning, Motivation and Relaxation. From the included studies, education delivery focussed upon on topics including knowledge of the disease, controlling breathlessness and anxiety management. Patients perceive this new knowledge is of benefit and it is positively received in facilitation of them learning to cope (Apps et al. 2013a, Bove et al. 2017, Meis et al. 2013), with patients believing the knowledge allows them to 'fight against' the disease in the context of self-managing (Apps et al. 2013a) as demonstrated within Table 21.

Table 21.0 - Reciprocal translations of included studies within the concept of enabling coping – Sub-themes: Education and Physical Functioning

Concept / - Categories	**Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]**	**Interpretations of findings offered by authors**
Enabling Coping - Education	'understanding the disease……. knowing what the long term effects are going to be' [5]	Variety of education topics required [5]
	'what's going on' [5]	Incorrect knowledge [9]
	'it's knowing the difference' [5]	Self-regulation [19]
	'leaning to cope' [5]	

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
	on your own, you're never sure whether 'your under-doing it or over-doing it' [5]	
	'need to know about oxygen' [5]	
	'you need to have knowledge of what's going on, because otherwise you cannot fight against it' [22]	
- Physical functioning	'I have really benefited from it' [1]	Increased coping behaviour [1]
	'And the exercise, I thought that was very important' [15]	
	'I feel good enough to get out of the door, under me own steam' [23]	
	'When I was walking with my wife, I had to stop. Now she has to stop' [1]	
	'I feel I am gaining in strength each week' [9]	
	'I have learnt that you can exercise best when breathing out……., I found this very strange but it is very important' [1]	

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
	'pacing themselves has helped control their breathlessness' [10]	

All included studies reported an increase in disease knowledge being of a perceived benefit by patients to some degree however within one study (Chen et al. 2016), it is reported that patients acquire this new knowledge through differing means such as healthcare professionals, friends and magazines, giving the potential for incorrect knowledge to be followed when self-managing. This evidence is supported through the work of Meis et al. (2013) whom identified patients often had incorrect disease knowledge impacting upon their ability to set realistic self-management goals and avoid the feeling of failure. The impact of this new knowledge, alongside exercise components within self-management interventions has led to improvements in participants physical functioning, with both perceptions of their ability to be more physically active alongside the ability to understand energy conservation to cope (Burkow et al. 2013, Meis et al. 2013, Monninkhof et al. 2004, Simpson and Jones 2013).

Table 22.0 - Reciprocal translations of included studies within the concept of enabling coping – Sub-theme: Motivation

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Enabling Coping	‘ it’s no good doing exercises, because you do them for a little while and then you leave it again’ [12]	
- Motivation	‘ have someone there who calls you up, and talks to you and encourages you gives you a little more will power’ [7]	Encouragement [12]
	‘the communication boosts me up, give me more courage’ [7]	Treatment beliefs affect participation [12]
- Motivation	‘when somebody is motivating you or checking in on you: you pay a little more attention to what you are doing’ [7]	
	‘I’m here to do this for my own benefit, not to please others’ [9]	
	‘remaining motivated (at home) will be hard’ [9]	
	‘you need to find a new rhythm back home. Structure and regularity are important’ [9]	

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
	'… if you got the recognition, it would be a motivating factor for me to go along….recognition of your own fear, panic, depression, anxiety' [12]	
	'I feel I am gaining in strength each week' [9]	

Motivation to participate within self-management interventions is triggered by feelings of achievement (Sohanpal 2015) alongside recognition from healthcare professionals of the severity of the impact of symptoms of COPD such as fear and anxiety (Meis et al. 2013). Motivation to continue to self-manage after an intervention was heavily influenced by the beliefs that to remain motivated at home, follow-up support is required. The feeling that a healthcare professional is checking upon the patient, encouraging and supporting them enables the patient to remain motivated and gives courage to continue (Benzo et al. 2013, Meis et al. 2013, Sohanpal 2015). Some studies reported participants' beliefs that their behaviour change would cease once at home without support (Meis et al. 2013, Sohanpal 2015), however no included study has reported upon patient self-management adherence post-intervention. A patient within one study (Meis et al. 2013), as shown within Table 22

reported the requirement of *'finding a new rhythm'* when no longer receiving the self-management intervention

Relaxation skills were deemed to be of importance to patients across the studies and reported by the original authors as a necessary component of self-management interventions. Mindfulness was explicitly explored within a single study (Harrison et al. 2016) and as a concept of relaxation was met with mixed response. Some patients believed it may provide them with clarity within their situation and could possibly assist with breathlessness whilst others felt that it was not a process for them and believed they could utilise their time more effectively in order to gain benefit upon their health. These patients also believed mindfulness should be offered as an optional therapy and not compulsory within self-management interventions to facilitate patient preference.

5.5 Wisdom

The concept of increased wisdom emerged in the analysis of this study. It evolved from the self-management interventions which were evident throughout all of the included studies, arguably with varying degrees of impact. This concept produced five sub-themes of enhanced knowledge leading to disease wisdom, energy conservation, increased self-efficacy, managing anxiety and treatment beliefs.

The sub-theme of enhanced knowledge leading to the feeling of increased wisdom (displayed within Table 23), was different to that described within enabling coping in section 5.4. Patients developed self-awareness secondary to detailed understanding of their disease. The opportunity to ask questions throughout interventions was perceived as a positive element to programmes of disease education and impacted upon the acquired self-awareness (Apps et al. 2013a, Meis et al. 2013, Wang et al. 2012).

Table 23.0 - Reciprocal translations of included studies within the concept of wisdom –Sub-themes: Enhanced Knowledge and energy conservation

Concept / - Categories	**Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]**	**Interpretations of findings offered by authors**
Wisdom Enhanced Knowledge	'put me on the track to many good ideas' [4]	Individualised information of benefit [4]
	'I like to be told about the reason we do all these things' [9]	Awareness of self [7]

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Enhanced knowledge	'Yes I think, possibly one thing to come out of it on the psychological side. It asks 'do you feel anxious or panicky? … i hadn't really thought about that' [14]	
	'And it was great to have the opportunity to ask questions' [15]	Knowing your disease [24]
	'Now I know I can take my reading; I can go out any day I want' [16]	
	'I just didn't think there was a need to phone them as there was nothing else I could have done' [16]	
	'well I wouldn't take my antibiotics straight away. I would just see what I was like within myself' [16]	
	'if something comes out (symptoms), you need to use your wisdom to solve the problem' [19]	

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Wisdom Energy conservation	'If I don't feel very well in the morning, then I have breakfast in my pyjamas and rest for a while and do everything in stages' [1]	Feeling safe [1]
	'If I get an attack, then I sit down…... this is a result of the education course' [1]	
	'I learnt to distribute energy evenly and listen to my body' [4]	
	'pacing themselves has helped control their breathlessness' [10]	

Within one study (MacNab et al. 2015), a patient had gained such disease awareness, they perceived they had the ability to understand when it was a good time to leave the house and another patient when deciding upon commencing medication stated *"well I wouldn't take my antibiotics straight away. I would just see what I was like within myself*', suggesting the acquisition of disease related wisdom to monitor changes within their condition. Interestingly, energy conservation was attributed to increased wisdom by patients adopting new ways of coping to achieve disease mastery. Patients voiced new ways of pacing themselves, re-ordering their morning routine to become less exhausted and listening to their body as ways of conserving their energy (Monninkhof et al. 2004, Wang et al. 2012).

Table 24.0 - Reciprocal translations of included studies within the concept of wisdom –Sub-themes: Increased self-efficacy and managing anxiety

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
- Increased self-efficacy	'You learn to pay attention to your body signals. You master everything better' [1]	Increased self-confidence [1]
	'I knew that I could treat myself' [1]	Aware of remaining capabilities [9]
	'I am more self-confident. When I started, I was very anxious and restless' [1]	Patients believe they already have the coping strategies [17]
	'Anything can be made smaller so you can handle it' [7]	
	'enabling control and taking decisions' [16]	
	'taking ownership, reducing reliance [16]	
	(When asked about increasing oxygen without healthcare professional advice) 'Well, I just took a little drop more' [17]	

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
- Managing anxiety	'I need to put into words how I feel, how I feel about the disease…'you have to be able to talk about anxiety…if you cannot manage your anxiety, you cannot manage anything else' [22].	Getting control of cognitions [22]
	'it's a matter of controlling the lungs that is so damn hard' [22]	Challenges to participation [23]
	'but the anxiety is located just between the ears right? It feel like dying a little bit I think' [22]	Sense of security and control [24]
	'I feel much of my shortness of breath is psychologically triggered' [22]	
	'I'm scared to get out of breath' [22]	

These two-sub-themes fed into the third of increased self-efficacy as the acquisition of wisdom increased patients' self-confidence, shown within Table 24. It was evident that as a result of self-management interventions, patients with COPD at the end of life became aware of their capabilities and were beginning to develop taking ownership of their disease and health. Some patients did report levels of increased self-efficacy that were potentially of danger, with one patient explaining how they decided to increase their oxygen therapy

without healthcare professional instruction (Mathar, Fastholm and Sandholm 2015), and within another study (MacNab et al. 2015), a patient no longer felt worth in contacting healthcare professionals as they perceived no further help could be given. The increased wisdom around self-management of anxiety was perceived to have both a positive impact upon coping and contrastingly causing challenges to participation within interventions (Bove et al. 2017, Nissen and Lindhart 2017). Some participants felt the interventions facilitated feelings of control around their anxiety (Nissen and Lindhart 2017) whereas other patients felt so anxious of the feeling of breathlessness that participation within elements of interventions such as exercise became psychologically difficult to commence (Bove et al. 2017)

5.6 – Healthcare Professionals Perspectives

The reduced confidence of healthcare professionals in patients' ability to change their health-related behaviour was a theme identified through included studies (Meis et al. 2013, Robinson et al. 2008b, Sohanpal 2015), with preconceptions of those living with COPD at the end of life influencing this as shown within Table 25.

Table 25.0 - Reciprocal translations of included studies within the concepts of preconceptions and insight

Concept / - Categories	**Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]**	**Interpretations of findings offered by authors**
- Preconceptions	'non-compliant' [2]	Fatalistic attitudes to COPD having significant impact upon care provision [2]
	'angry' [2]	Healthcare professionals find patient attitudes to self-management frustrating [2]
	'frustrated' [2] 'just close the door (to any possibility of change)' [2]	Resignation [12]
	'we'll try and educate them but they don't seem to want to listen' [2]	

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
	'(patients) become more the disease than the person with the disease….so you just see them as a package of symptoms' [2]	
	'the blue bloater……they seem to have lost themselves' [2]	
	'they tend to deny their illness [9]	
	'Feel they are entitled to be a burden' [12]	
- Insight	'there are great differences in intelligence between patients. Some patients can't make their own choices; they completely rely on others '[9]	
	Patients frequently find it hard to show that they are ill' [9]	
	'it's important they want to change' [9]	
	'they do not have enough insight in the disease, they cannot judge the seriousness and then they yo-yo should I do it or wait a day' [11]	

Feelings that patients are angry and frustrated are commonly identified and these perceptions facilitate healthcare professionals to believe the patients do not wish to change their coping behaviours (Robinson et al. 2008b). Some negative comments were identified as to how patients with COPD are perceived including 'the blue bloater' and 'you just see them as a package of symptoms' (Robinson et al. 2008b),portraying the image that some healthcare professionals to believe patients with COPD to be a burden. Alongside this as displayed within Table 25, it is believed by healthcare professionals that patients with COPD at the end of life do not have enough insight into how to cope with their disease, resulting in the patients being unable to self-manage effectively (Davies et al. 2014, Meis et al. 2013, Robinson et al. 2008b). This finding contrasts with the perceptions of patients given within section 5.5, of their increased wisdom and perception of coping following a self-management intervention.

These perceptions did alter for some healthcare professionals following participation in the delivery of self-management interventions, most evidently within their new found ability to relate to the patient's behaviours from living with a debilitating long-term condition as shown within Table 26.

Table 26.0 - Reciprocal translations of included studies within the concept of change in perceptions and insight

Concept / - Categories	**Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]**	**Interpretations of findings offered by authors**
Change in Perceptions	'relate to where some of their negative attitudes come from' [2]	Reconstructing healthcare professional practice [2]

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Change in Perceptions	'(acceptance of patient's position) on a good day we'll do this and if it's a not so good day we'll do the other' [2]	Broadening of understanding [2]
	'we must look at ourselves as health professionals…….changing our learnt behaviours towards management of these clients' [2]	Perceptions of patients changed from fatalistic to speaking of them holistically describing them as individuals [2]
	'see if we can get positive outcomes for the people in general' [2]	Need to remain open to self-management as a healthcare professional [2]
	'determine what they perceive as important to themselves, because I think that will help their general sense of wellness' [2]	Trust from healthcare professional in patient's capabilities [11]
	'this will never happen, I can never do this……..she's done her garden [2]	Use e-heath data as an education tool [16]

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Change in perceptions	'they've got their goals and people are taking notice of them…That's got her motivated' [2]	Education key element [18]
	'there's a lot of use for this in our work' [2]	Mindfulness can control clinical symptoms [20]
	'led to clients becoming viewed as a whole person' [2]	Incorporate clients views of the world [2]
	'it sort of has changed my perception quite a lot [8]	Change required in behaviour of healthcare professionals [6]
	'you see patients who are really stunned by their achievements' [9]	
	'it definitely increases their self-confidence' [9]	
	'it makes me feel good when patients have become more independent' [9]	
	'my goal is to help patients achieve their own goals' [9]	

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Change in Perceptions	'see if we can get positive outcomes for the people in general' [2]	Need to remain open to self-management as a healthcare professional [2]
	'determine what they perceive as important to themselves, because I think that will help their general sense of wellness' [2]	Trust from healthcare professional in patient's capabilities [11]
	'this will never happen, I can never do this……..she's done her garden [2]	Use e-heath data as an education tool [16]
	'they've got their goals and people are taking notice of them…That's got her motivated' [2]	Education key element [18]
	'there's a lot of use for this in our work' [2]	Mindfulness can control clinical symptoms [20]
	'led to clients becoming viewed as a whole person' [2]	
	'it sort of has changed my perception quite a lot [8]	
	'it's allowing them to have a little bit of time……for me to shut up' [8]	

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Change in perceptions	'you see patients who are really stunned by their achievements' [9]	
	'gives them a feeling of reward' [9]	
	'it definitely increases their self-confidence' [9]	
	'it makes me feel good when patients have become more independent' [9]	
	'my goal is to help patients achieve their own goals' [9]	

This sense of working with patients holistically indicates the healthcare professionals adopt a wider appreciation for the needs of patients with COPD at the end of life when promoting self-management. A strong sense of perceived achievement for the patient was displayed within healthcare professional's views following self-management intervention delivery with comments including 'you see patients who are really stunned by their achievements' (Meis et al. 2013) and the intervention 'led clients to becoming viewed as a whole person' (Robinson et al. 2008b).

Table 27.0 - Reciprocal translations of included studies within the concept of barriers to implementation

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Barriers to implementation	'you just feel like a failure in terms of making progress' [2]	
	'I don't feel like I am doing anything and then I think we lose interest in it' [2]	
	'I know it sounds awful but it was like teaching us to suck eggs' [8]	
	'we can point, take a horse to water but we can't make him drink' [8]	
	'oh no, not another thing coming at us' [8]	
	'I think it's important that patients set reachable goals, if they don't, they fail, which affects their self-confidence' [9]	
	'Thinking about advanced disease, that's quite a shock and I don't think we're confident to discuss that with them' [21]	Barriers to goal setting [2]

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Barriers to implementation	'I think relapse is mainly due to poor self-management skills' [9]	Comprehensive training required for healthcare practitioners [25]
	'I do not trust patients in this way. I cannot prescribe it to everyone' [11]	No experience of behaviour change management [18]
	'……this requires not only familiarity, but a very good patient…..not only about familiarity here it is about, trust on both sides' [11]	Perception of self-management being not enough to warrant extra effort professionally [8]
	'it's probably not good for everyone, it's not that everyone feels like taking actions independently' [11]	Light-touch service led the healthcare professionals to believe they were offering inadequate support [16]
	'giving someone ten, fifteen, twenty minutes, half an hour as a one off is often not the way in which to address these more complex patient problems [14]	COPD specific knowledge [21]

Concept / - Categories	Quotations from participants in primary studies [Study reference number as detailed within Table 9.0]	Interpretations of findings offered by authors
Barriers to implementation	'consultation time for COPD patients is short…..understanding and then prepare the guidelines for them, it takes time' [11]	Duplication of care given by other services[14]
		Choosing the right patient. Only suitable for a minority [11]
	'where you get a patient that is self-managing better….they cut out the clinician completely then… but that patient can then sometimes fall off the radar' [16]	Confusion with pulmonary rehabilitation [18]
	'I haven't got any experience of setting goals in a structured way' [18]	Nurses recognised importance yet misunderstood definitions [18]
	'I never really know what's out there for them' [21]	

When delivering self-management interventions, some healthcare professionals believed the promotion of self-management was similar to the routine care they already delivered, and at

times believed it was an added workload burden – ‘I know it sounds awful but it was like teaching us to suck eggs’ (Kennedy et al. 2014). Healthcare professionals perceived they did not have enough time within their working day to deliver the interventions (Buckingham et al. 2015, Davies et al. 2014, Kennedy et al. 2014), as demonstrated within Table 27.

A further restriction was the perception of giving the patients they cared for the coping skills through self-management interventions, yet the patients were not inclined to participate (Kennedy et al. 2014, Meis et al. 2013, Robinson et al. 2008b). Healthcare professionals believe self-management is not appropriate for every patient and needs to be individualised and addressed appropriately to those for which it is suitable (Davies et al. 2014, Meis et al. 2013).

When specifically discussing the use of self-management for those patients with advanced COPD at the end of life, it was perceived that the healthcare professionals do not have the required knowledge to confidently discuss this stage of disease progression with the patients (Reinke et al. 2011).

The sub-theme of collaboration between healthcare professionals and patients was underpinned by the perceptions that historically healthcare professionals give patients a solution to a problem, therefore facilitating patient self-management becomes a challenge (Benzo et al. 2013, Kennedy et al. 2014, Robinson et al. 2008b). The requirement to receive further training on self-management delivery to enable patients to self-manage was fuelled by beliefs that healthcare professionals find difficulty in approaching new topics with patients (Kennedy et al. 2014, Meis et al. 2013, Robinson et al. 2008b).

Chapter 6.0 – Discussion

This chapter brings together the key findings from this systematic review to provide an evaluation of the perceived effect of self-management as a coping strategy for people with COPD at the end of life through the exploration of the views of patients, their carers and healthcare professionals. The further aim of this dissertation was to determine at what point within disease progression a self-management programme would benefit people with COPD at the end of life.

This chapter is divided into five sections. The first section (6.1) is a discussion of the main study findings. The identified study limitations are presented within section 6.2. The implications of this research for clinical practice are described within section 6.3 and the exploration of future research is given in section 6.4. Section 6.5 draws together the final conclusions of this dissertation.

6.1 – Main Findings

The exploration of the use of self-management interventions for patients with advanced COPD at the end of life is novel. Whist patients with COPD at the end of life have been included in a number of self-management research studies, no study has explicitly explored their experiences from the perspectives of patients and healthcare professionals. The study findings suggest that people with COPD at the end of life face a plethora of physical and social symptoms impacting upon their ability to self-manage, yet interventions enhancing patient's abilities to self-manage with COPD at the end of life are perceived by patients and healthcare professionals as having a positive effect. The use of self-management enhancing interventions for people with COPD at the end of life comes with some considerations to overcome barriers to implementation and success as perceived by both patients and healthcare professionals.

Further, the review interestingly revealed that patients with COPD at the end of life have not always accepted that they have a chronic disease, even at such an advanced stage. From the wider literature, one theory that explores factors upon the hindrance of COPD disease acceptance is the feeling of guilt by the individual as a result of the condition being perceived as self-inflicted due to smoking (Lindquist and Halberg, 2010), and as a result, patients deny their symptoms and the impact of the condition to ease these feelings (Ngyuen, 2013). This systematic review also identifies the perceptions of healthcare professionals. These feelings of denial and resistance to change in patients with COPD at the end of life are echoed within the perceptions of healthcare professionals who believe disease acceptance creates a barrier to participation within self-management activity. A further explanation of reluctance of disease acceptance is the association between disease knowledge and increased feelings of fear of symptoms, and how the condition will affect their quality of life. This study aligns with the work of Stenzel et al. (2015) who identified that following a diagnosis of COPD, disease

related anxieties are present and often result in fears upon the end of life. Contrastingly, the wider literature suggests the need for increased disease knowledge is key to disease acceptance (Jones 2007, Gardener 2018), and subsequent health behaviour change (Borbeau, 2004). The recent work of Weldam et al. (2017) has tried to address how the perceptions of patients with COPD can be used, with the assistance of a healthcare professional, to allow patients a better understanding of their disease related behaviours and from this develop action plans to improve health outcomes, daily functioning and health related behaviours. The study findings demonstrated no long-term impact of this approach to facilitating disease acceptance (Weldam et al. 2017). This systematic review challenges such evidence in light of the findings that patients with COPD at the end of life may never accept their disease and may continue to resist the acquisition of disease related knowledge as a form of self-preservation. This requires the approach to using self-management interventions for patients with COPD at the end of life to be given further consideration to account for their non-acceptance of disease. As identified by Effing et al. (2016), self-management interventions should focus upon the setting of realistic personal goals with the adaptation of delivery strategies changed to meet them. A surprising finding from this systematic review was the preconceptions of healthcare professionals who perceived patients with COPD at the end of life to be reluctant to changing their healthcare behaviours. Healthcare professionals found this situation to be frustrating, yet could be linked to the avoidance of disease acceptance form patients. This study highlighted the need for further education for healthcare professionals upon the underpinning reasons behind non-acceptance of disease in order to allow the delivery and content of programmes of self-management to consider this within its approach.

These preconceptions continued past healthcare professionals perceptions of patients being reluctant to change their healthcare behaviours. It became clear that this resulted in patients with COPD being defined by the disease and their required needs, rather than as individuals. Patients with COPD are deemed complex to manage and this can be challenging for

healthcare professionals. This may result in the patient being perceived as 'unpopular' as first explored by Stockwell (1972), whom identified patients who strayed from the expected behaviour set by nurses were believed to be difficult. This view challenged the expectations that nurse would treat every patient with a non-judgemental approach and following further exploration (Carveth, 1995), patients who required extra recovery time and caused disruption to planned workloads labelled as difficult. A further review of this concept (Conway, 2000), identified patients who resist treatment compliance were also perceived as difficult. This study adds to this knowledge base, with the healthcare professionals perceptions of patients with COPD at the end of life being labelled as *'frustrating'*, '*difficult', 'non-compliant' and 'angry'*. Further work is required to explore these healthcare professional perceptions of patients with COPD at the end of life to determine the full extent of the impact upon patient care provision.

The review identified the use of self-management interventions implies the withdrawal of dependence upon healthcare professionals and is a common aim within self-management studies. When hoping to assist in enhancing the abilities to self-manage for patients with COPD at the end of life, the removal of all dependence is both unnecessary and unrealistic. The dependence of patients upon reassurance of differing types was highlighted throughout the study, with patients gaining this from a range of sources. It was evident from this review that the need for dependence upon healthcare professionals was underpinned by overwhelming feelings of solitude. Self-management interventions created feelings of safety and trust, removing the expected intervention benefits away from the patients self-managing and more value being placed upon the direct healthcare professional contact. Opposing to this, the wider literature outside of this review has focussed the purpose of self-management interventions being to enable patients to better manage their condition independently, and reduce the requirement for healthcare professional contact (Borbeau et al. 2003, Gadoury et al. 2005), however this study identifies this would not be a suitable aim for those with COPD at the end of life. Patients with COPD require some degree of healthcare professional

contact throughout the palliative phase of the disease, due to their deterioration in condition resulting in changing needs. Consideration needs to be given to the creation of a hybrid model linking both continued and self-management care between patients and healthcare professionals to meet the needs of the patients who are nearing the end of life, with the overarching realistic aim of developing patient autonomy as opposed to complete independence.

Dependence upon family members and carers was also evident within this study however none of the included studies explored the perceptions of carers upon the use of self-management within COPD at the end of life, highlighting the need for further research in this area to determine their perceptions upon effect alongside the nature of impact upon them as carers. A recent study exploring the agreement of symptom burden between patients with advanced COPD and carers (Mi et al. 2018) identified that carers may struggle to easily accept symptoms and the consequent impact, resulting in carer perception of a greater symptom burden. The study continues to suggest the need for further exploration of the impact upon patients and carers psychological status within advanced COPD, which is currently being undertaken.

The perceived patient results of participation within the studies drawn highlighted that the self-management interventions were positive, suggesting the acquisition of new skills enabled them to improve coping abilities at the end of life. This was a very positive result. Further an increase in disease related wisdom presented as a strong theme in the review having positive impact upon coping abilities, particularly around models of energy conservation and the enhance coping associated with new methods of undertaking daily activities. This finding enhanced pre-existing knowledge around the benefits of energy conservation techniques assisting with coping for patients with COPD, hence the adoption within Pulmonary Rehabilitation programmes (Velloso et al. 2006). The inclusion of such techniques within self-management interventions for patients with COPD at the end of life is crucial to develop individual's abilities to adapt their behaviours to assist coping.

A further increase in disease related wisdom was supported by increased self-efficacy, a finding identified within this systematic review. Patients perceived they had more self-confidence to take ownership of their condition consequently enabling them to have more control upon their symptoms. Whilst this is a positive finding from this study, increased self-efficacy requires careful application of intent when designing self-management interventions for patients with COPD at the end of life. Within a study evaluating the effect of a comprehensive care management programme to prevent COPD related hospital admissions (Fan et al. 2012), a statistically significant incidence of mortality within the intervention group resulted in the study being prematurely terminated. The underpinning cause of mortality remains unknown, however does raise caution when facilitating increased patient self-efficacy, particularly within such a vulnerable group of patients due to the unpredictability of disease trajectory within COPD at the end of life. Consideration does need to be given to the potential implications of patients abstaining from seeking healthcare input when unwell due to their increased belief they are able to manage their condition independently however this brings great challenges to healthcare professionals when delivering interventions aiming to increase self-efficacy yet ensure the patient maintains their ability to identify when they require help.

This review has shown that patients prefer self-management interventions to be delivered by healthcare professionals who have specialist knowledge of the disease. This preference is echoed by the perceptions of healthcare professionals within this study who believe that non-specialists do not have the required disease and behavioural change knowledge to feel comfortable within self-management intervention delivery. This finding contrasts with the UK model of healthcare, whereby the National COPD Management Guidelines (National Institute for Clinical Excellence, 2010), whilst advocating self-management, stipulate patients with COPD at the end of life are delivered care by multi-disciplinary care teams whom are most likely not COPD specialists. This is further supported by the work of Elkington (2004) whom identified respiratory nurses are rarely involved within the palliative phase of COPD illness.

To compliment the current UK healthcare model, whilst addressing the patient requirement of specialist input to enhance self-management at the end of life, a programme of education for non-specialist multi-disciplinary team members is required to equip them with the necessary knowledge and skills to deliver this, however, the development of such a programme brings challenges of time, resources and funding to healthcare providers.

Interestingly, the review showed that determining at what point within disease progression a self-management intervention is required to be implemented to have effect at the end of life remains unknown, despite being an aim of this study. From the patient and healthcare professionals perspectives in the systematic review, the acquisition of disease knowledge is preferred early within disease progression to allow time for adaptation and behaviour change, yet in light of the study's findings upon disease acceptance this would not suit the preferences of all patients. This study evaluated the perceptions of patients whom were already at the end of life at the time of intervention delivery therefore further research is required to explore the effect of the timing of delivery of an intervention early within disease progression upon patients abilities to cope at the end of life.

6.2 – Study Limitations

This systematic review followed robust pre-defined methods to search, select and analyse the included data to explore the perceptions of patients, carers and healthcare professionals upon the use of self-management as a coping strategy for patients with COPD at the end of life. Prior to determining the inclusion and exclusion criteria for this review, a definition of end of life COPD was decided upon. As there is no gold standard definition of COPD at the end of life, as identified within chapter 2, the definition used within this review may be identified as a limitation to this review as a result of different interpretations of the elements used to determine this stage in disease progression. Further to this, a definition of self-management was established to use within the review and is again subject to differences of opinion in light of the absence of an approved definition for use within healthcare interventions.

A very broad search of 12 databases was undertaken to minimise study exclusion limitations. This study is limited by the selection of original data reported within the included studies as given by each original author.

The systematic review adopted a novel meta-ethnographical underpinning with the findings analysed using a refutational synthesis approach to create new concepts to further understand the use of self-management as a coping strategy for people with COPD at the end of life. Alternative methods of data synthesis could have been selected to analyse the findings such as a thematic synthesis that may demonstrate variations within the findings. A meta-ethnographical approach was most suitable to meet the aims of this study as it allowed for the perceptions of patients from each included study to be synthesised into larger concepts to create a stronger impact when influencing patient care.

Finally, as a systematic literature review is never complete, regular revisions of this review will be undertaken in light of any further studies being published meeting the inclusion and exclusion criteria of the review

6.3 – Implications for clinical practice

In view of the new evidence revealed from this systematic review, the use of self-management as a coping strategy for people with advanced COPD at the end of life is acceptable to patients and healthcare professionals, however the differences between the perceptions are evident. This study will inform healthcare professionals of patient's preferences when delivering self-management interventions to those with COPD at the end of life to enable an understanding of what patients need to assist with enhancing self-management behaviours.

This review has identified the need for further education and self-management delivery training for healthcare professionals responsible for caring for patients with COPD at the end of life, particularly those within non-respiratory specialist roles who deliver care to this cohort of patients. This training is required to focus upon patients who resist disease acceptance, giving the rationale underpinning this to change the perceptions of healthcare professionals of this cohort of patients. Further education of healthcare professionals is required upon behaviour change techniques to ensure they are equipped with the required knowledge and skills to facilitate enhancing patients self-management abilities to provide high quality evidence based care to patients. Further work is also required to address the preconceptions of healthcare professionals of patients with COPD at the end of life to minimise the impact these views have upon care delivery.

This study has also highlighted the preference for face-to-face self-management intervention delivery as opposed to the use of more remote methods of delivery such as technological aids. This is particularly evident when discussing issues upon patients end of life choices and care and requires consideration when delivering care to patients with COPD at the end of life.

6.4 – Future Research

This dissertation has identified the need for further research into how disease acceptance affects the abilities of patients with COPD at the end of life to enhance their self-management skills and to explore ways to overcome this potential barrier.

The development, testing and evaluation of impact of a specific end of life COPD self-management intervention is now urgently required building on the findings from this study. One study should focus upon the need for a supported approach to access palliative care provision alongside enhancing patients abilities to self-manage. A further study is required to facilitate the use of self-management as a coping strategy for patients with COPD at the end of life into clinical practice to determine if its impact does improve the patient experience at the end of life.

Alongside this, the creation of an educational intervention for healthcare professionals responsible for facilitating the care of patients with COPD at the end of life is required to be explored and evaluated to determine the required components to impact upon palliative care provision for patients with COPD.

6.5 – Final conclusions

This study explored the perceptions of patients and healthcare professionals upon the use of self-management enhancing interventions for patients with COPD at the end of life through a systematic review of 25 qualitative studies. The studies were analysed and synthesised using a novel meta-ethnographical approach to create firm concepts upon the impact of self-management interventions within this cohort of patients.

The review found that the use of self-management interventions for patients with COPD at the end of life is perceived by patients and healthcare professionals as having a positive effect upon their ability to cope with the overwhelming symptoms at this stage of disease progression. From the review, patients with COPD at the end of life disliked the increased dependence that resulted from having such an illness. Specific interventions were critically considered in the results of the review which may reduce the need for high dependence and create an enhanced feeling of self-control.

Despite the aims of this systematic review being met, further work is urgently required to address the education and training needs of healthcare professionals when managing and facilitating self-management skills to patients with COPD at the end of life. Alongside this, the facilitation of a self-management intervention, with palliative care components is required to be implemented into clinical practice to evaluate its impact upon patient experience at the end of life. Only then will improvements in this field begin.

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Appendices

Appendix A – BCT Taxonomy (v1): 93 hierarchically-clustered techniques (Michie et al. 2013)

Page	Grouping and BCTs	Page	Grouping and BCTs	Page	Grouping and BCTs
1	1. Goals and planning	8	6. Comparison of behaviour	16	12. Antecedents
	1. 1.1. Goal setting (behavior) 2. 1.2. Problem solving 3. 1.3. Goal setting (outcome) 4. 1.4. Action planning 5. 1.5. Review behavior goal(s) 6. 1.6. Discrepancy between current behavior and goal 7. 1.7. Review outcome goal(s) 8. 1.8. Behavioral contract 9. 1.9. Commitment		6.1. Demonstration of the behavior 6.2. Social comparison 6.3. Information about others' approval		1. 12.1. Restructuring the physical environment 2. 12.2. Restructuring the social environment 3. 12.3. Avoidance/reducing exposure to cues for the behavior 4. 12.4. Distraction 5. 12.5. Adding objects to the environment 6. 12.6. Body changes
3	2. Feedback and monitoring		7. Associations		13. Identity
	2.1. Monitoring of behavior by others without feedback 2.2. Feedback on behaviour 2.3. Self-monitoring of behaviour 2.4. Self-monitoring of outcome(s) of behaviour 2.5. Monitoring of outcome(s) of behavior without feedback 2.6. Biofeedback 2.7. Feedback on outcome(s) of behavior	9 10 11 12 15	7.1. Prompts/cues 7.2. Cue signalling reward 7.3. Reduce prompts/cues 7.4. Remove access to the reward 7.5. Remove aversive stimulus 7.6. Satiation 7.7. Exposure 7.8. Associative learning 8. Repetition and substitution 8.1. Behavioral practice/rehearsal 8.2. Behavior substitution 8.3. Habit formation 8.4. Habit reversal 8.5. Overcorrection 8.6. Generalisation of target behavior 8.7. Graded tasks		1. 13.1. Identification of self as role model 2. 13.2. Framing/reframing 3. 13.3. Incompatible beliefs 4. 13.4. Valued self-identify 5. 13.5. Identity associated with changed behavior
5	3. Social support		9. Comparison of outcomes	17 18 19 19	14. Scheduled consequences 14.1. Behavior cost 14.2. Punishment 14.3. Remove reward 14.4. Reward approximation 14.5. Rewarding completion 14.6. Situation-specific reward 14.7. Reward incompatible behavior 14.8. Reward alternative behavior 14.9. Reduce reward frequency 14.10. Remove punishment
	3.1. Social support (unspecified) 3.2. Social support (practical) 3.3. Social support (emotional)		9.1. Credible source 9.2. Pros and cons 9.3. Comparative imagining of future outcomes 10. Reward and threat 10.1. Material incentive (behavior) 10.2. Material reward (behavior) 10.3. Non-specific reward 10.4. Social reward 10.5. Social incentive 10.6. Non-specific incentive 10.7. Self-incentive 10.8. Incentive (outcome) 10.9. Self-reward 10.10. Reward (outcome)		15. Self-belief 1. 15.1. Verbal persuasion about capability 2. 15.2. Mental rehearsal of successful performance 3. 15.3. Focus on past success 4. 15.4. Self-talk
6	4. Shaping knowledge				16. Covert learning
	4.1. Instruction on how to perform the behavior 4.2. Information about Antecedents 4.3. Re-attribution 4.4. Behavioral experiments				16.1. Imaginary punishment 16.2. Imaginary reward 16.3. Vicarious consequences
7	5. Natural consequences				
	5.1. Information about health				

	consequences 5.2. Salience of consequences 5.3. Information about social and environmental consequences 5.4. Monitoring of emotional consequences		10.11. Future punishment 11. Regulation		

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Appendix C – Systematic Review Protocol

A qualitative systematic review of using self-management as a coping strategy to meet the needs of patients with advanced chronic obstructive pulmonary disease at the end of life: Protocol

Registration

In accordance with the guidelines, our systematic review protocol was registered with in International Prospective Register of Systematic Reviews (PROSPERO) on 18th December 2017 (Registration Number 83741)

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Support

The systematic review is supported by the National Institute for Health Research/Health Education England as a part of a funded Masters by Research programme at Coventry

University.

This protocol sets out the methods to be used within this systematic review to determine if self-management is an effective coping strategy for patients with advanced chronic obstructive pulmonary disease at the end of life. The protocol has been structured using the PRISMA-P (2015) framework for systematic review protocols.

Underpinning this work will be a meta-ethnographical approach, sitting firmly within the interpretivist philosophical paradigm, allowing findings around the beliefs, attitudes and perspectives of the study participants to be translated into each other to develop new concepts. In turn, this will present transferable findings into how patients take care of themselves at the end of life and the effectiveness of coping skills interventions for patients in the advanced stages of COPD and potentially other life-limiting conditions. As a result of this underpinning, quantitative studies have been excluded from this review as they do not provide the required data type. This research gives focus to key healthcare priorities, which include preventing people from dying prematurely, enhancing quality of life for people with long-term conditions and ensuring that people have a positive experience of care.

Objectives

The aim of this systematic review is to evaluate the potential effect of self-management as a coping strategy upon patients with advanced COPD at the end of life.

The proposed systematic review will achieve the following objectives:

- To identify empirical qualitative research relevant to self-management within COPD at the end of life.
- To identify relevant empirical qualitative research that has examined the perspectives of patients, carers and healthcare professionals upon self- management at the end of life.
- To determine by drawing from the literature at what point within COPD disease progression a self-management programme would benefit a patient with COPD at the end of life.
- To critically appraise and synthesise this data to identify, explore and explain if self-management is a potential coping strategy for patients with COPD at the end of life.

Rationale

Description of the Condition

Chronic Obstructive Pulmonary Disease (COPD) presents when irreversible airflow limitation is present, resulting in symptoms of breathlessness, increased sputum production, chronic cough and wheezing. Exacerbations of COPD cause acute deterioration. Furthermore, as identified by Lozano et al. (2010:2096), COPD is characterised by systemic co-morbidities that include cardiac disease, diabetes mellitus, hypertension osteoporosis and psychological disorders.

COPD is a major cause of morbidity and mortality and as identified by the World Health Organisation (2015), is the fourth biggest cause of death worldwide. Within the UK, over 30,000 deaths are attributed to COPD each year, with over 1.2 million individuals currently diagnosed with the disease. The British Lung Foundation's Battle for Breath report (2016:18) state COPD is responsible for 1.7% of all hospital admissions within the UK. The impact of this life threatening condition extends past physical symptoms, as identified by Elkington et al. (2004), with COPD causing impairment in individuals working and daily lives, including social isolation and co-morbid depression and anxiety.

Description of the Intervention

Attempts to define self-management, when used as a tool to improve patient care and experience has been attempted many times, making it difficult to ascertain which elements lead to its success. It is well documented that self-management has a strong focus upon the patient taking responsibility for their own health and social outcomes but how that responsibility is gained is variable. Barlow et al. (2002:178) defines self- management as 'the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition'. Lifestyle changes are evident throughout COPD disease progression and include decreased mobility, increased breathlessness and anxiety. They continue to state that for self-management be successful and sustainable, the individual must be able to alter the way they think, behave and emotionally react to managing their chronic condition. This in turn will lead to them having the ability to respond to the demands of the disease.

In addition to this, Effing et al. (2012:27) state behaviour change is a fundamental property of sustaining better control of one's health. As identified by Wagg (2012:6), studies including behaviour change elements, for example motivational interviewing, demonstrate positive outcomes in improving quality of life yet that further research into the effect of such psychological interventions within self-management programmes is necessary.

To further understand behaviour change and the effective elements of the approach, the Behavioural Change Taxonomy devised by Mitchie et al. (2013) explains the components necessary to assist with the process. The taxonomy was specifically designed to identify the effective components within a programme of behaviour change and is relevant and transferable to self-management within chronic disease. To assist a participant with a change in behaviour, based on the taxonomy, one or more of the following components, listed in a decreasing hierarchy, must be included:

- Behavioural goal setting and action planning
- Monitoring and feedback on behaviour
- Practical and emotional social support
- New knowledge acquisition
- Behavioural change effects
- Comparing behaviour to others
- Triggers to abstaining from behaviour change
- Practicing new behaviours
- Positives and negatives of changing a behaviour
- Rewarding new behaviour
- Behaviour regulation
- Amendments to the physical and social environment
- Understanding a new identity
- Self-efficacy
- Covert learning

Mitchie et al. (2013:6)

Having reviewed the work of leading self-management studies for patients with COPD, such as the work of Apps et al. (2013), Wagg (2012) and Gadoury (2005), effective components

of self-management programmes include an educational or skill development component, anxiety management and action planning. Based upon the components of the behavioural change taxonomy and what has already been seen to be effective within these studies, this systematic review will review papers including one or more of the following elements. The format of delivery will not be restricted to allow for understanding the effectiveness of each method for example verbal, written, audio-visual.

- Decision-making techniques
- Symptom monitoring skills
- Action planning and Goal setting
- Emotional management techniques
- Problem solving techniques
- Increased participant confidence
- Action planning and goal setting
- Behavioural-change techniques
- Exacerbation management techniques
- New knowledge component
- Practicing new behaviours

Research has been undertaken to implement and evaluate self-management interventions within COPD in earlier stages of the disease, where attendance at educational sessions is possible and presents varying degrees of success. A standardised self-management manual, SPACE for COPD has been developed for individuals with COPD, demonstrating improvements in exercise capacity and breathlessness for participants as reported by Apps et al. (2013:327). This manual is focused on self-management throughout all stages of the disease, however did not specifically evaluate its effect within the palliative phase of illness. Many self-management interventions encompass a pharmacological component such as the use of stand-by antibiotics and steroids for the patient to commence should they feel there is a requirement when beginning an exacerbation period. There is anecdotal concern amongst respiratory specialists around over-prescription and over-use of these medications and questions raised that other self-management interventions may be as, if not more effective. Technology-based self-management interventions have also been explored by McCabe et al. (2017), however lack evidence of benefit to the quality of life for patients with COPD or reduction in acute hospital admissions. Difficulties when implementing this type of intervention are enhanced with this particular cohort of patients

whom are frail, isolated and older and may potentially cause barriers at a time of need. For individuals living with COPD, the disease progression inevitably leads towards palliative symptom management, encompassing the patient's ability to cope and manage their illness more effectively in the face of impending death,

Public Health England (2013)

Evaluating self-management and coping interventions for people with COPD at the end of their life is little investigated. There are several gaps in our understanding of optimal self-management, particularly when a patient is nearing the end of life, when exacerbations are more frequent, have an increased vulnerability and lack the coping skills they may have had when more well. There is uncertainty as to when a self-management intervention should commence to impact positively on quality of life and reduces access to healthcare services when the patient is within the palliative phase of illness. Should the intervention be implemented early within disease progression, the patient may dismiss its existence from their mind over time or contrastingly, implementation at this time may allow the patient to embed new coping strategies to become usual behaviour, thus continuing into the palliative phase of the disease. The needs of patients with COPD at the end of life may be different to those earlier within disease progression. The symptoms are commonly predicted and include social isolation, anxiety, depression and increasing dependence often resulting in patients accessing healthcare services to assist. Should these patients have the skills and self-efficacy to manage these symptoms independently, the need for access to healthcare services at this stage in disease progression could decrease, alongside supporting patient choice around where they die. To further understand when this intervention would be of benefit, understanding when and how we can classify a patient with COPD is at the end of life is crucial.

Defining when a person is at the end of life encompasses many components and is complex in nature. As identified by the Gold Standards Framework Centre in end of Life Care (2011:1), a high probability of death within the next 12 months suggests that person is nearing the end of life. Predicting death is both complex and difficult and comes with a degree of uncertainty. The Gold Standards Framework Centre in End of Life Care (2011:1) has attempted to facilitate making this prediction by suggesting the use of three triggers to

indicate a person is approaching or are within their last phase of life. The first trigger, “The surprise question’ asks, if as a healthcare practitioner, you would be surprised if this person died within the next few months, weeks or days? Secondly, ‘General Indicators’ are reviewed determining the person’s decline in health, and increasing demand for support with functional needs. These indicators include:

- Reduction in activity and performance status
- General decline in physical ability
- Reduction in the response to previously used treatments
- Progressive weight loss
- Repeated hospital admissions which are unplanned

The third trigger, is the consideration of organ failure. The following indicate, more specifically for patients with COPD, that they may be nearing the end of their life:

- Disease presenting as severe (<30% FEV1)
- Repeated unplanned hospital admissions due to exacerbations of COPD
- Signs of right sided heart failure
- Fulfils the criteria for long-term oxygen therapy
- More than 6 weeks of steroid therapy within the last 6 months for COPD

Concurrent to this, classification tools are available for use in determining a person’s severity of COPD, which are used as a prognostic indicator. The rationale for COPD assessment being to determine the severity of airflow limitation, the impact on a person’s health status and functional ability including exacerbations of COPD, hospital admissions and death. The two most commonly adopted tools are the Global initiative for Chronic Obstructive Lung Disease (GOLD) Staging System (2017) and the Body-mass index, airflow Obstruction, Dyspnoea, and Exercise (BODE) Index created by Powrie (2004). The BODE Index originated from a study concluding the four factors to best predict a person’s COPD prognosis were their Body Mass Index (BMI), their degree of airflow obstruction (post bronchodilation FEV1), dyspnoea (measured using the MMRC score) and exercise tolerance. Each factor is scored 0-3 (0-1 for BMI). The greater the BODE index score, the higher risk of patient death.

The GOLD assessment tool (2017:6) aims to separately consider the following aspects of

disease:

- Severity of spirometric abnormality
- Current nature and severity of person's symptoms
- Exacerbation history and future risk
- Presence of co-morbidities such as diabetes mellitus, heart failure and psychological disorders.

The assessment of the severity of spirometric abnormality is classified as shown within table 1.0

Table 1.0

GOLD 1:	Mild	FEV1 >80% predicted
GOLD 2:	Moderate	50% <FEV1> 80% predicted
GOLD 3:	Severe	30% <FEV1> 50% predicted
GOLD 4:	Very Severe	<30% FEV1 Predicted

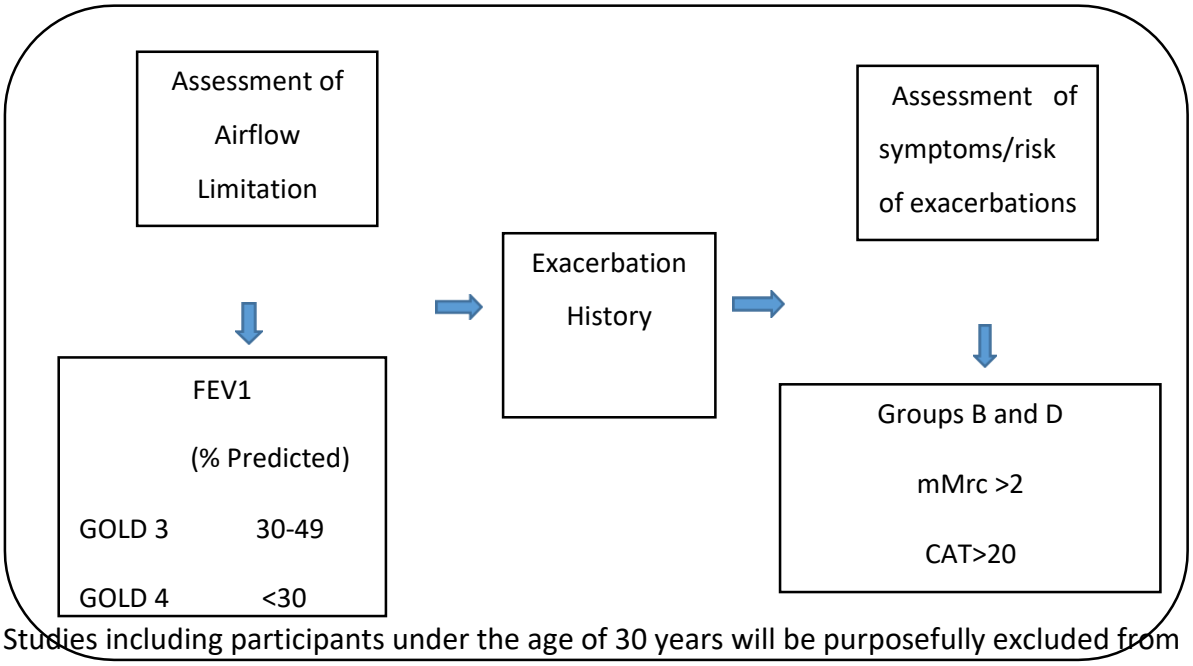
As acknowledged by Jones (2001), the relationship between lung function and health status is weak, therefore requiring symptomatic assessment is required to determine prognosis. Measuring a person's heath status with COPD is again facilitated by an evidence based tool. The two most commonly used being the Modified British Medical Research Council (mMRC) Questionnaire and the COPD Assessment Test (CAT).

The mMRC Questionnaire focuses upon that person's degree of breathlessness when undertaking activities of living such as incline walking and dressing or undressing. Jones (2001:881) identifies COPD controls more than breathlessness alone and therefore an inclusive measurement of symptoms is recommended by the Global initiative for Chronic Obstructive Lung Disease (2017:6). The COPD Assessment Test (CAT) as explained by Jones et al. (2009:652) will 'aid health status assessment and communication between patient and physician'. The COPD Assessment Test (CAT) is a questionnaire designed to assess the impact of the disease upon a person's quality of life, with a maximum score of 40 being the biggest impact. In view of the GOLD (2017) COPD assessment guidelines, the aforementioned assessment criteria are combined alongside the GOLD (2017) ABCD grouping system (to predict the patients risk of exacerbations and assessment of symptoms

in conjunction with either an mMRC or CAT score to comprehensively assess a patients stage of COPD disease progression.

Determining at what stage in GOLD disease progression a person will be when they die is difficult and survival statistics for each of the stages are difficult to collate. GOLD (2017) do stress the importance of mortality prediction at individual patient level. As previously explained, when a person with COPD is nearing the end of life lung function decline is present, with increased percentage of airflow restriction. Therefore, GOLD stages 3 and 4 would suggest a person is moving towards the end of life, however that decision is not to be made from this one single measurement and assessment of other related symptoms is required and is necessary to predict prognosis. The revised GOLD (2017) revised ABCD assessment tool combines the spirometric assessment with the risk of COPD exacerbations and symptom burden. Group B describes the person as having a low risk of exacerbations and more symptoms, and Group D describes a high risk of exacerbations and more symptoms. Soriano et al. (2015) explain that an increase in exacerbations alongside increased symptoms suggest an increased risk of mortality, suggesting these two group classifications would be the most appropriate indicators to attempt to predict COPD end of life.

For the purpose of this systematic review, the definition of COPD at the end of life will be as follows:



Studies including participants under the age of 30 years will be purposefully excluded from

this review due to the evidenced link between premature birth and chronic lung disease.

Eligibility Criteria

Study Designs

Inclusion

- Studies containing any type of qualitative data (e.g. interviews, focus groups, workshops).
- Exploratory studies.
- Randomised Controlled Trials will be included should they contain a qualitative element.
- Intervention studies
- Single case studies
- Systematic and other literature based reviews
- Theoretical studies related to the chosen intervention subject.
- PhD Theses.

Exclusion

- Quasi-experimental studies
- Trial evaluations
- Quantitative data collection studies
- First person narrative studies

Participants/Population

Studies will be included or excluded based on the following criteria:

Inclusion:

- Studies including participants over 30 years old with a diagnosis of COPD at GOLD Stage 3 or 4/CAT Score of greater than 20/ Group B or D.
- Studies including participants with advanced COPD of mixed age groups if the results of above and below 30 years old are separated.
- Studies including participants of either gender.
- Studies including healthcare professionals of any profession (eg. Nurse, Doctor, Allied Health Professional), who care for patients with COPD at GOLD stage 3 or 4 at the end of life.
- Studies including carers of any description (eg. Family members, paid carers).

Exclusion:

- Studies including participants with a diagnosis of COPD at an earlier stage in disease progression (GOLD Stage 1 or 2/CAT Score of less than 20/mMRC>20/Group A or C).
- Studies including participants with a diagnosis of another chronic disease at an earlier than advanced stage in disease progression.
- Studies including participants under 30 years of age.
- Study participants involved in evaluating a trial.

Interventions

- Patient groups that have a diagnosis of COPD at GOLD stage 3 or 4 (Groups B or D) with a mMrc of greater than 2 or CAT score of greater than 20 who have participated in a self-management intervention study.
- The self-management intervention must include one or more of the following components:
- Decision-making techniques
- Symptom monitoring skills
- Action planning and Goal setting
- Emotional management techniques
- Problem solving techniques
- Increased participant confidence
- Action planning and goal setting
- Behavioural-change techniques
- Exacerbation management techniques
- New knowledge component
- Practicing new behaviours

Comparators

Not applicable.

Timing

Studies will not be included if published prior to 1990 due to this being the start of the literature upon the specified area of study.

Setting

There will be no restrictions by type of setting.

Language

Articles will be included in the English and English American languages.

Information Sources

Literature search strategies will be developed using subject headings and key text words related to self-management in COPD at the end of life.

We will search the following databases at each specified frequency:

Academic Search Complete (1990 onwards) - Weekly

AMED (1990 onwards) - Weekly

CINAHL (1990 onwards) - Weekly

Cochrane Database (1990 onwards) - Monthly

EThOS – British Library Theses (1990 onwards) – Monthly

Family Health Database (1990 onwards) - Weekly

Medline (1990 onwards) - Weekly

ProQuest Nursing and Allied Health Source (1990 onwards) - Weekly

Psychology Database (1990 onwards) - Weekly

PsychInfo (1990 onwards) - Weekly

SCOPUS (1990 onwards) - Weekly

PROSPERO (1990 onwards) - Weekly

All databases will be accessed through the EBSCOhost platform.

The literature search will be limited to the English and English American languages and human subjects.

To ensure a robust literature search, we will review the reference lists of each included study identified within the search.

Search Strategy

The search will identify both qualitative and mixed methods studies. No restrictions on study design will be included within the search. Only studies in the English or American English languages will be included within the study.

The specific search strategy will be developed by the lead researcher and reviewed by a specialist Health Sciences Librarian with experience in systematic review searching.

The aforementioned databases will be searched alongside PROSPERO for systematic reviews currently ongoing or recently completed.

The MEDLINE search will be developed by the lead researcher and approved by the contributors and a specialist Health Sciences Librarian. Upon finalisation of the MEDLINE search strategy, it will be adapted to the requirements of other databases.
A draft Medline search strategy is included in Appendix D.

Study Records

Data Management

The results of the literature search will be uploaded onto the Distiller Systematic Review (DSR) software, an online program to allow for citation abstracts to be uploaded and screened against pre-determined questions formulated from the inclusion and exclusion criteria to reduce potential errors through data entry.
The program also allows for reviewers to collaborate throughout the study.

A calibration exercise will be undertaken prior to formally screening the results, to allow for the refinement of the screening questions.

Selection Processes

All records identified from the search will be uploaded to the DSR software and abstract screened against pre-determined questions formulated from the inclusion and exclusion criteria. Those screened for inclusion by abstract will then be full-text screened by two reviewers who unanimously make a decision for final inclusion. Any discrepancy for inclusion or exclusion will be resolved by a third reviewer.

Data Collection Process

Data extracted from the included studies will be undertaken by two reviewers. Any discrepancy for inclusion or exclusion will be resolved by a third reviewer.
The criteria for data extraction, based upon the Critical Skills Appraisal Programme (2017) and underpinned by a meta-ethnographical data synthesis approach will include the following elements. A pilot data extraction exercise will be undertaken using a random sample from the included studies and the criteria for data extraction amended as required. The critical appraisal of all included studies will determine its reliability, validity and relevance to the area of study. Studies of poor reliability or validity will remain within the results however the weight held within the conclusions will be proportionate to its worth.

Outcomes

Primary Outcomes

A meta-ethnographical synthesis of qualitative findings to create new concepts to determine if self-management is an effective coping strategy for patients with COPD at the end of life.

Secondary Outcomes

An understanding of the perspectives of relatives, carers and healthcare professionals involved in the care of patents engaged within COPD self-management at the end of life.

To understand the elements of COPD self-management programmes that are of particular significance in creating a successful coping strategy for patients at the end of life.

Risk of Bias in individual studies

All full-text articles included within the review will be assessed for quality using the Cochrane Risk of Bias Tool (Cochrane Online 2017).
This tool allows the researcher to assess the risk of bias under four domains, Selection bias, Performance bias, Detection bias, Attrition bias and Reporting bias.
The quality of a paper will not automatically depict inclusion or exclusion. The quality assessment will determine the weight of argument within the review findings.

Data Synthesis

A meta-ethnographical approach will be adopted to synthesise the qualitative findings within the search results. The work of Noblit and Hare (1988) will be utilised to structure this process.
The studies will be read and re-read multiple times to identify themes and concepts within them. Concepts extracted from each study will be clustered and analysed then translated into predominant new concepts for presentation.
The original concept from within each study will be consulted to ensure it is sustained within the interpretation and formulation of predominant concepts.

Confidence in cumulative estimate

The GRADE (Grades of recommendation, assessment, development and evaluation), created by Guyatt et al. (2008) will be used to rate the quality of evidence extracted from the included studies to evaluate the weight of concepts presented.

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Appendix D – Draft Medline Search Strategy

Draft MEDLINE Search

COPD search terms:

Chronic Obstructive Pulmonary Disease
COPD
Respiratory Disease
Emphysema
Long-term conditions
Respiratory conditions
COPD Management
COPD treatment
OPD interventions
COPD exacerbation
Pulmonary disease

Self-management search terms:

Self-management/ self-management
Self-care/ self care
self-car
Symptom monitoring
Symptom
Goal setting
Emotional management
Emotion
Anxiety management
Problem solving
Confidence
Action plan/ Action-plan
Behavioural change
Behaviour change
Exacerbation management
Resilience
Emotional
behav
Self-efficacy/self efficacy
Empower
Training
train
Decision-making
Decision
Techniques
New knowledge
New behaviours
Behaviour

End of life search terms

Death

Dying
Dies
Died
Palliative care
Palliative
End of life
Life end
Terminal

Appendix E – Data extraction Proforma Document

Data Extraction Table – Based upon Critical Skills Appraisal Programme (2017)

Author:

Paper Title:

Heading	Sub-Heading	Information to extract	For Completion by Reviewer
Background	Bibliographic Details		Publication Year Year of Data Collection Country of origin
	Typology	Must be of type listed within pre-defined criteria.	Qualitative Research Exploratory Studies RCT's with qualitative data Intervention Study Systematic/Literature Review Theoretical Study PhD Thesis
	Definition of End of Life COPD	Must fit with pre-defined definition.	
	Definition of Self-Management	Must include one or more of the pre-defined criteria.	
	Participants		Patients with COPD at End of Life. Family and/or carers of patients with COPD at End of Life. Healthcare professionals
Ethical Standards		Adequate ethical consideration? Appropriate ethical process followed?	Yes No
Context	Aims of the Study	Are the aims and purpose of the study clearly defined? What was the goal of the research? Importance of the research	Yes No
Setting	Setting of study	What is the geographical setting of the study?	Primary care Secondary care Other: _____

Heading	Sub-Heading	Information to extract	For Completion by Reviewer
	Timing	Over what time period did data collection take place? What was the length of the follow up period?	
Sample	Inclusion Criteria	Who was included in the study?	
	Exclusion Criteria	Who was excluded from the study?	
	Selection	How was the sample selected? Any influences on sample selection?	
	Size	What is the size of the sample?	
	Appropriateness	Is the sample appropriate to meet the aims of the study?	
Data Collection	Methods	What methods were used? Was data collection adequately described and rigorously conducted? Is the method appropriate for the aim of the research?	
	Role of the researcher	What was the role of the researcher? Conflicts of interest	
	Data Analysis	How are the data analysed? Adequate description of data analysis? Is adequate evidence provided to support the analysis? Rigorous analysis?	
	Researcher's potential bias	Is any potential bias acknowledged?	

Heading	Sub-Heading	Information to extract	For Completion by Reviewer
	Reflexivity	Has the researcher's values and beliefs affected their work? Implications of findings considered?	
Findings	Themes/Concepts	Are they explicit? Can other themes be identified? Do the findings relate to the original research question? Do the themes fit with those found within other studies?	
	Conclusions	Valid conclusions made?	
	Opinions	What this researcher argues	
Other comments	Value	How valuable is the research? Impact upon research and patient care?	

Appendix F - PRISMA-P 2015 Checklist

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
ADMINISTRATIVE INFORMATION					
Title					
Identification	1a	Identify the report as a protocol of a systematic review	√		Appendix C – Page 171
Update	1b	If the protocol is for an update of a previous systematic review, identify as such			Not Applicable
Registration	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract	√		Appendix C – Page 171
Authors					
Contact	3a	Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author	√		Appendix C – Page 171
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review		√	
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments		√	Not Applicable
Support					
Sources	5a	Indicate sources of financial or other support for the review	√		Appendix C – Page 171
Sponsor	5b	Provide name for the review funder and/or sponsor	√		Appendix C – Page 171
Role of sponsor/funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	√	☐	Appendix C – Page 171
INTRODUCTION					
Rationale	6	Describe the rationale for the review in the context of what is already known	√		Appendix C – Page 173
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	√		Appendix C – Page 172
METHODS					
Eligibility criteria	8	Specify the study characteristics (e.g., PICO, study design, setting, time frame) and report characteristics (e.g., years considered, language, publication status) to be used as criteria for eligibility for the review	√		Appendix C – Page 180
Information sources	9	Describe all intended information sources (e.g., electronic databases, contact with study authors, trial registers, or other grey literature sources) with	√		Appendix C – Page 182

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
		planned dates of coverage			
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	√		Appendix D
STUDY RECORDS					
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	√		Appendix C – Page 183
Selection process	11b	State the process that will be used for selecting studies (e.g., two independent reviewers) through each phase of the review (i.e., screening, eligibility, and inclusion in meta-analysis)	√		Appendix C - 184
Data collection process	11c	Describe planned method of extracting data from reports (e.g., piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	√		Appendix C – Page 184 and pro-forma document in Appendix E.
Data items	12	List and define all variables for which data will be sought (e.g., PICO items, funding sources), any pre-planned data assumptions and simplifications	N/A		
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	√		Appendix C – Page 184
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	√		Appendix C – Page 185
DATA					
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized			N/A
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g., I^2, Kendall's tau)			N/A
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression)			N/A
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	√		Meta-ethnography explained – Appendix C – Page 185
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies)	√		Appendix C – Page 185
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (e.g., GRADE)	√		Appendix C – Page 185

Appendix G - Full Search Terms and Syntax

Database: **Academic Search Complete** <1990 to 25th April 2018>	
Search Strategy 1	
1	Chronic Obstructive Pulmonary Disease/ or COPD/ or Respiratory Disease/ or Emphysema/ or Long-term conditions/ or Respiratory Conditions/ or COPD management/ or COPD treatment/ or COPD interventions/ or COPD exacerbation/ or Pulmonary Disease
2	Self-management/ or self-management/ or self-care/ or self care/ or *self-car*/ or symptom monitoring/ or symptom/ or goal setting/ or emotional management/ or emotion/ or Anxiety management/ or Problem solving/ or Confidence/ or Action Plan/ or Action-Plan/ or Behavioural change/ or Behaviour change/ or Exacerbation management/ or Resilience/ or Emotional/ or Emotion/ or *behav*/ or self-efficiacy/ or self efficacy/ or empower/ or Training/ or *train*/ or Decision-making/ or Decision techniques/ or new knowledge/ or new behaviours/ or behaviour
3	Death/ or dying/ or dies/ or died/ or palliative care/ or palliative/ or end of life/ or life and/ or terminal
4	Limits: Search terms found in Title OR Abstract/ Human Participants/ English Language
5	1 AND 2 AND 3 – Three term search (314)
6	1 AND 2 – Two Term search (279, 834)

Database: **AMED** <1990 to 25th April 2018>	
Search Strategy 2	
1	Chronic Obstructive Pulmonary Disease/ or COPD/ or Respiratory Disease/ or Emphysema/ or Long-term conditions/ or Respiratory Conditions/ or COPD management/ or COPD treatment/ or COPD interventions/ or COPD exacerbation/ or Pulmonary Disease
2	Self-management/ or self-management/ or self-care/ or self care/ or *self-car*/ or symptom monitoring/ or symptom/ or goal setting/ or emotional management/ or emotion/ or Anxiety management/ or Problem solving/ or Confidence/ or Action Plan/ or Action-Plan/ or Behavioural change/ or Behaviour change/ or Exacerbation management/ or Resilience/ or Emotional/ or Emotion/ or *behav*/ or self-efficiacy/ or self efficacy/ or empower/ or Training/ or *train*/ or Decision-making/ or Decision techniques/ or new knowledge/ or new behaviours/ or behaviour
3	Death/ or dying/ or dies/ or died/ or palliative care/ or palliative/ or end of life/ or life and/ or terminal
4	Limits: Search terms found in Title OR Abstract/ Human Participants/ English Language
5	1 AND 2 AND 3 – Three term search (389)
6	1 AND 2 – Two Term search (2614)

Database: **CINHAL** <1990 to 25th April 2018>	
Search Strategy 3	
1	Chronic Obstructive Pulmonary Disease/ or COPD/ or Respiratory Disease/ or Emphysema/ or Long-term conditions/ or Respiratory Conditions/ or COPD management/ or COPD treatment/ or COPD interventions/ or COPD exacerbation/ or Pulmonary Disease
2	Self-management/ or self-management/ or self-care/ or self care/ or *self-car*/ or symptom monitoring/ or symptom/ or goal setting/ or emotional management/ or emotion/ or Anxiety management/ or Problem solving/ or Confidence/ or Action Plan/ or Action-Plan/ or Behavioural change/ or Behaviour change/ or Exacerbation management/ or Resilience/ or Emotional/ or Emotion/ or *behav*/ or self-efficiacy/ or self efficacy/ or empower/ or Training/ or *train*/ or Decision-making/ or Decision techniques/ or new knowledge/ or new behaviours/ or behaviour
3	Death/ or dying/ or dies/ or died/ or palliative care/ or palliative/ or end of life/ or life and/ or terminal
4	Limits: Search terms found in Title OR Abstract/ Human Participants/ English Language
5	1 AND 2 AND 3 – Three term search (8099)
6	1 AND 2 – Two Term search (142)

Database: **Family Health Database** <1990 to 25th April 2018>	
Search Strategy 4	
1	Chronic Obstructive Pulmonary Disease/ or COPD/ or Respiratory Disease/ or Emphysema/ or Long-term conditions/ or Respiratory Conditions/ or COPD management/ or COPD treatment/ or COPD interventions/ or COPD exacerbation/ or Pulmonary Disease
2	Self-management/ or self-management/ or self-care/ or self care/ or *self-car*/ or symptom monitoring/ or symptom/ or goal setting/ or emotional management/ or emotion/ or Anxiety management/ or Problem solving/ or Confidence/ or Action Plan/ or Action-Plan/ or Behavioural change/ or Behaviour change/ or Exacerbation management/ or Resilience/ or Emotional/ or Emotion/ or *behav*/ or self-efficiacy/ or self efficacy/ or empower/ or Training/ or *train*/ or Decision-making/ or Decision techniques/ or new knowledge/ or new behaviours/ or behaviour
3	Death/ or dying/ or dies/ or died/ or palliative care/ or palliative/ or end of life/ or life and/ or terminal
4	Limits: Search terms found in Title OR Abstract/ Human Participants/ English Language
5	1 AND 2 AND 3 – Three term search (139,005)
6	1 AND 2 – Two Term search (629)

Database: **Psychology Database** <1990 to 25th April 2018>	
Search Strategy 5	
1	Chronic Obstructive Pulmonary Disease/ or COPD/ or Respiratory Disease/ or Emphysema/ or Long-term conditions/ or Respiratory Conditions/ or COPD management/ or COPD treatment/ or COPD interventions/ or COPD exacerbation/ or Pulmonary Disease
2	Self-management/ or self-management/ or self-care/ or self care/ or *self-car*/ or symptom monitoring/ or symptom/ or goal setting/ or emotional management/ or emotion/ or Anxiety management/ or Problem solving/ or Confidence/ or Action Plan/ or Action-Plan/ or Behavioural change/ or Behaviour change/ or Exacerbation management/ or Resilience/ or Emotional/ or Emotion/ or *behav*/ or self-efficiacy/ or self efficacy/ or empower/ or Training/ or *train*/ or Decision-making/ or Decision techniques/ or new knowledge/ or new behaviours/ or behaviour
4	Limits: Search terms found in Title OR Abstract/ Human Participants/ English Language
5	1 AND 2 – Two Term search (238, 560)

Database: **PsychINFO** <1990 to 25th April 2018>	
Search Strategy 6	
1	Chronic Obstructive Pulmonary Disease/ or COPD/ or Respiratory Disease/ or Emphysema/ or Long-term conditions/ or Respiratory Conditions/ or COPD management/ or COPD treatment/ or COPD interventions/ or COPD exacerbation/ or Pulmonary Disease
2	Self-management/ or self-management/ or self-care/ or self care/ or *self-car*/ or symptom monitoring/ or symptom/ or goal setting/ or emotional management/ or emotion/ or Anxiety management/ or Problem solving/ or Confidence/ or Action Plan/ or Action-Plan/ or Behavioural change/ or Behaviour change/ or Exacerbation management/ or Resilience/ or Emotional/ or Emotion/ or *behav*/ or self-efficiacy/ or self efficacy/ or empower/ or Training/ or *train*/ or Decision-making/ or Decision techniques/ or new knowledge/ or new behaviours/ or behaviour
3	Death/ or dying/ or dies/ or died/ or palliative care/ or palliative/ or end of life/ or life and/ or terminal
4	Limits: Search terms found in Title OR Abstract/ Human Participants/ English Language
5	1 AND 2 AND 3 – Three term search (3)
6	1 AND 2 – Two Term search (72)

Database: **SCOPUS** <1990 to 25th April 2018>	
Search Strategy 7	
1	Chronic Obstructive Pulmonary Disease/ or COPD/ or Respiratory Disease/ or Emphysema/ or Long-term conditions/ or Respiratory Conditions/ or COPD management/ or COPD treatment/ or COPD interventions/ or COPD exacerbation/ or Pulmonary Disease
2	Self-management/ or self-management/ or self-care/ or self care/ or *self-car*/ or symptom monitoring/ or symptom/ or goal setting/ or emotional management/ or emotion/ or Anxiety management/ or Problem solving/ or Confidence/ or Action Plan/ or Action-Plan/ or Behavioural change/ or Behaviour change/ or Exacerbation management/ or Resilience/ or Emotional/ or Emotion/ or *behav*/ or self-efficiacy/ or self efficacy/ or empower/ or Training/ or *train*/ or Decision-making/ or Decision techniques/ or new knowledge/ or new behaviours/ or behaviour
3	Death/ or dying/ or dies/ or died/ or palliative care/ or palliative/ or end of life/ or life and/ or terminal
4	Limits: Search terms found in Title OR Abstract/ Human Participants/ English Language
5	1 AND 2 AND 3 – Three term search (32, 578)
6	1 AND 2 – Two Term search (235, 431)

Database: **Nursing and Allied Health Source** <1990 to 25th April 2018>	
Search Strategy 8	
1	Chronic Obstructive Pulmonary Disease/ or COPD/ or Respiratory Disease/ or Emphysema/ or Long-term conditions/ or Respiratory Conditions/ or COPD management/ or COPD treatment/ or COPD interventions/ or COPD exacerbation/ or Pulmonary Disease
2	Self-management/ or self-management/ or self-care/ or self care/ or *self-car*/ or symptom monitoring/ or symptom/ or goal setting/ or emotional management/ or emotion/ or Anxiety management/ or Problem solving/ or Confidence/ or Action Plan/ or Action-Plan/ or Behavioural change/ or Behaviour change/ or Exacerbation management/ or Resilience/ or Emotional/ or Emotion/ or *behav*/ or self-efficiacy/ or self efficacy/ or empower/ or Training/ or *train*/ or Decision-making/ or Decision techniques/ or new knowledge/ or new behaviours/ or behaviour
4	Limits: Search terms found in Title OR Abstract/ Human Participants/ English Language
5	1 AND 2 – Two Term search (303, 206)

Database: **Cochrane Database of Systematic Reviews** <1990 to 25th April 2018>	
Search Strategy 9	
1	Chronic Obstructive Pulmonary Disease/ or COPD/ or Respiratory Disease/ or Emphysema/ or Long-term conditions/ or Respiratory Conditions/ or COPD management/ or COPD treatment/ or COPD interventions/ or COPD exacerbation/ or Pulmonary Disease in Record Title
2	Self-management/ or self-management/ or self-care/ or self care/ or *self-car*/ or symptom monitoring/ or symptom/ or goal setting/ or emotional management/ or emotion/ or Anxiety management/ or Problem solving/ or Confidence/ or Action Plan/ or Action-Plan/ or Behavioural change/ or Behaviour change/ or Exacerbation management/ or Resilience/ or Emotional/ or Emotion/ or *behav*/ or self-efficiacy/ or self efficacy/ or empower/ or Training/ or *train*/ or Decision-making/ or Decision techniques/ or new knowledge/ or new behaviours/ or behaviour in Record Title
3	Number of Results: 83

Database: **Ethos Thesis Database** <1990 to 25th April 2018>	
Search Strategy 9	
1	Chronic Obstructive Pulmonary Disease/ or COPD/ or Respiratory Disease/ or Emphysema/ or Long-term conditions/ or Respiratory Conditions/ or COPD management/ or COPD treatment/ or COPD interventions/ or COPD exacerbation/ or Pulmonary Disease in Record Title
2	Self-management/ or self-management/ or self-care/ or self care/ or *self-car*/ or symptom monitoring/ or symptom/ or goal setting/ or emotional management/ or emotion/ or Anxiety management/ or Problem solving/ or Confidence/ or Action Plan/ or Action-Plan/ or Behavioural change/ or Behaviour change/ or Exacerbation management/ or Resilience/ or Emotional/ or Emotion/ or *behav*/ or self-efficiacy/ or self efficacy/ or empower/ or Training/ or *train*/ or Decision-making/ or Decision techniques/ or new knowledge/ or new behaviours/ or behaviour in Record Title
3	Number of Results: 92